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TITLE: Aging Families and Breast Cancer: Multigenerational  
Issues

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<b>13. ABSTRACT (Maximum 200 Words)</b> With the continuing shift of cancer care to community-based care the necessity to develop programs that will enable the family to meet patients' needs for support and assistance is of paramount importance. Overall goal of this exploratory investigation is to obtain information the will: identify adult daughter caregivers in need of psychosocial support interventions to enable them to meet their mothers' needs for illness-related emotional support and assistance; reduce daughter' emotional stresses associated with this support role, and, enable the daughters to continue their caregiving role. To accomplish these objectives we are collecting data from a sample of older women receiving treatment for breast cancer and their adult caregiving daughters. The patients and their daughters each complete a questionnaire and the daughters complete a focused interview. Activities for Year 3 have focused on ongoing sample accrual and data collection, analysis of data, and dissemination of project findings through conference presentations, invited lectures and publications. Study data supports the conclusion that cancer is a disease that impacts or affects the family unit, not just he patient. Programs and services are needed that target the family and support not only the patient but the special needs of family members. While family members may be regarded as part of the care team, they are also affected by the cancer experience. It needs to be more commonly acknowledged/recognized that they hold a dual status.				
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## **INTRODUCTION**

Life expectancy has increased dramatically in recent decades, producing an equally impressive expansion in the size of the elderly population. However, little attention has been given to cancer in the aged. Even less is known about the psychosocial problems experienced by older breast cancer patients and their families, as very little empirical research has focused on understanding the dynamics of older women's support networks. In particular, adult daughters, who are likely to be a primary source of support and assistance to older women, have not been a focus of research investigations or supportive services although they are likely to experience a high demand for emotional support themselves.

The overall purpose in conducting this exploratory investigation is to obtain information that: identifies caregivers in need of psychosocial support interventions to enable them to meet their relatives' needs for illness-related emotional support and assistance; reduces daughters' emotional stresses associated with this support role; and, enables the familial caregiver to continue their caregiving role. To accomplish these objectives we are conducting an intensive (in-depth) investigation to gain insights and generate provisional hypotheses, rather than estimate specific population parameters. We are using a methodology that is suited to the exploratory nature of the investigation, relying primarily on qualitative data gathering (focused/ethnographic interviews) and data analytic techniques (e.g., thematic and content analysis). We are collecting data from a sample of older women receiving treatment for breast cancer and their caregiving daughters. The patients and their daughters each complete a structured questionnaire. The daughters also participate in a focused interview.

The activities for Year 3 have focused on: subject recruitment, data collection, processing of the quantitative data, coding and analysis of the focused interviews, and disseminating study findings. These activities will be continued throughout Year 4. See Appendix A for IRB approval of the continuing investigation.

## **BODY**

The study's overall objective is to obtain exploratory, descriptive information that will inform critical gaps in the knowledge base and provide insights for clinical management of women with breast cancer and affected family members. Qualitative research is often used as an exploratory research strategy when the current state of knowledge about the phenomenon under investigation is limited or not well understood. Qualitative approaches are particularly suitable for understanding individual perspectives when such perspectives are likely to be complex and contextual and may change or evolve over time. It is a means of obtaining the insider's view, permitting one to take into account cultural, social and contextual circumstances. The research accomplishments conducted during Year 3 reflect this approach. These activities are described below organized by task. These activities will continue throughout Year 4 of the project.

### ***Task 1: Subject recruitment and data collection***

- a. Potentially eligible cases identified from ongoing review of clinic and hospital records*
- b. Potentially eligible patient-daughter dyads contacted, screened and accrued*
- c. Questionnaire data collected from patient-daughter dyads*
- d. Focused interviews conducted with caregiving daughters*

Accrual is ongoing to obtain a sample of older women receiving treatment for breast cancer and their adult caregiving daughters. Potentially eligible patients are identified from continuous review of the breast cancer patient population at the Herbert Irving Comprehensive Cancer Center, whose catchment area includes diverse socioeconomic and racial/ethnic neighborhoods. Permission to approach potentially eligible patients (i.e., diagnosed with breast cancer, in active treatment, aged 60+) is acquired from the patient's physician. Once permission is received, these patients are sent a letter informing them about the study. Included with the letter is a return post card with a check-off for persons who do not wish to be contacted. A clinician researcher then contacts potential participants by telephone to discuss the study further, determine their eligibility and, if they are interested in participating, determine whether the patients have a caregiving daughter who is 21+, a biological daughter, does not have a history of cancer and is involved in providing practical assistance and support to the patient. The clinician researcher then obtains permission from any patient who is eligible and interested in the study, to contact the daughter for study participation. The daughter is then sent a letter, followed by a phone conversation with the clinician researcher about the study. Only those patient-daughter dyads in which both members are willing to participate are accrued.

Table 1 presents the distribution by eligibility and participation status of the pool of potentially eligible patient cases identified to date. As can be seen, the eligibility status of 51% of the patient pool could not be determined, primarily due to patient refusal to be contacted (n=83) or patient/daughter refusal to be screened (n=50). For an additional 35 cases, the patient was unable to be reached, and in three instances the patient died prior to being contacted.

To date, from the pool of patients, about a third (34%) were determined to be ineligible for the study. The major reason that a patient was ineligible was that she did not have a daughter (n=71). The second ineligibility reason was that the patient's daughter was not a caregiver to the mother (n=38). There was also one case in which the patient did not reside in the U.S. permanently and was only in residence while receiving treatment for her breast cancer. Generally, once an eligible patient was identified, the daughter was also found to be interested in participating in the study. About 79% of the eligible patient-daughter dyads agreed to participate in the study (n=41).

To date, we have accrued 41 dyads. Forty-one patient questionnaires have been completed, 39

daughter questionnaires have been completed and 39 daughter focused interviews have been conducted.

Table 2 depicts the distribution of the patient sample (n=41) that has been accrued into the study to date. In keeping with the racial and ethnic mix of the hospital catchment area, 71% of the patients are white, 22% are Hispanic and 5% are black. More than half of the patients (54%) are currently married. Another 29% are widowed, and 17% are divorced or separated. Sixty-one percent of participants are among the young-old (i.e., 60-69 years old), and 39% among the old-old (i.e., 34% aged 70-79 and 5% aged 80 or older). About two-thirds of the patients (68%) have been diagnosed with local breast cancer. While all of the patients have received surgery for their cancer, 37% of the patients have also had radiation and 27% have had chemotherapy.

Standard sociodemographics and lifestyle data are being collected in the mother and daughter questionnaires. Information is also being obtained on health status, health history, psychosocial well-being, caregiving situation and the quality of the familial caregiver/patient relationship. This information is being used to describe the sample, not estimate specific population parameters. The quantitative data analyses are also being used to contextualize the analyses of the daughters' narrative reports. As discussed below, NVivo can import this data directly into the qualitative files.

The qualitative data collected from the daughters' focused interviews reflect the study goal of discovering participants' personal "definition of the situation" (e.g., breast cancer experience) and understanding their lived experiences. The interview process aims to elicit the meanings that daughters ascribe to the cancer-related events and circumstances that may shape these processes. Thus, the topic guide includes discussion of issues related to (a) diagnosis, illness, and treatment (e.g., circumstances leading to the mothers' diagnosis, daughters' reactions to their mothers' illness and treatment experiences); (b) cancer risk (e.g., daughters' perceived vulnerability to cancer, their health monitoring plans and disease-prevention practices); (c) caregiving (e.g., daughters' caregiving burden, their need and receipt of emotional support and practical assistance); (d) lifestyle changes (e.g., changes in family roles and functioning since the inception of the illness, impact of the illness on daughters' quality of life, work, and future goals); and (e) fertility/child-rearing (e.g., the effects of their mothers' breast cancer on daughters' fertility decisions and on child-rearing practices).

### ***Task 2: Data processing of quantitative (structured questionnaire) data***

- a. *Patient and daughter questionnaires edited, coded and data entered into computer databases*
- b. *Data cleaning of questionnaire data implemented*
- c. *Construction of analytic data files from quantitative data*

Once a patient or daughter questionnaire has been completed, it is edited and coded; the

responses are then entered in a computer database. As part of the data entry program, a variety of data cleaning and data checking procedures have been written into the program. This ensures that out-of-range punches, miscodes and "Does not apply" sections are identified and errors are corrected.

***Task 3: Coding and textual analysis of qualitative (focused interview) data***

- a. Transcripts of audiotaped focused interviews entered into computer text files*
- b. Coding scheme developed for focused interviews*
- c. Reading, reviewing and re-reading of focused interview transcripts*
- d. Codes and subcodes assigned to relevant textual material*
- e. NVivo codes inserted into computer text files of focused interviews*
- f. Construction of analytic topic files from qualitative data*

The focused interviews conducted with the daughter are audiotaped, with the daughter's permission. These audiotapes are then transcribed and entered into computer text files for analysis and textual coding. The focused interviews are transcribed on an ongoing basis. The transcriptions are then reviewed and coded. To ensure that the coding scheme for the codes was valid (well grounded in the data and supportable) and reliable (consistent in meaning), it was developed in a systematic manner. Specifically, material from the interview transcripts was read, reviewed, and coded by two independent readers. These coders identified broad themes relevant to the foci of analysis. These themes were then assigned "core" codes. In turn, "secondary" codes were developed that represented more specific or restricted aspects of the theme, contextualized the theme, or indicated the daughters' personal meanings underlying the theme.

Using this process a coding manual was prepared, that includes a common set of themes derived from the interview data and a common set of criteria to assign numeric values to the themes, core codes, and secondary codes. Working independently, coders assign numeric values to each identified segment of text. Coding discrepancies are resolved through joint discussion and verification of the text with other interviews having the same code, in an effort to arrive at a consensus between the readers about the appropriate coding. In keeping with the exploratory goals of the investigation, any additional themes emerging from the text are being integrated into the interview topic guide, as appropriate.

***Task 4: Dissemination of study finding***

- a. Analysis of the quantitative and qualitative data carried out*
- b. Manuscripts, presentations, study reports prepared*

The coded transcriptions of the focused interviews are being analyzed with NVivo, qualitative software that assists in the qualitative data analyses. NVivo supports code-based inquiry, searching, and theorizing, combined with the ability to annotate and edit documents. It produces

frequency counts for core or secondary codes by case, designated subgroups, or total data file. Text can be searched for and transported by a core or secondary code or any code combination. The analyses that are being conducted on the study data are exploratory in nature. They are designed to explore and assimilate the rich (i.e, thick, fluid and complex) data. Nvivo is being used to conduct text searches, text retrieval, and identification of themes, concepts, and variables. In addition, the quantitative data obtained from the patient and daughter questionnaires can be accessed through NVivo to contextualize the analysis of the quantitative data and permit exploratory subgroup analyses. That is, any measures collected as part of the questionnaire can be imported through NVivo into the qualitative files.

During Year 3, several conference presentations and invited lectures were presented and publications were prepared. These are described below in, see **“Year Three: Key Research Accomplishments”**, and the presentations or manuscripts included in the appendices.

### **YEAR THREE: KEY RESEARCH ACCOMPLISHMENTS**

As described above field activities have been ongoing throughout Year 3. We have continued to:

- Accrue patient-daughter dyads
- Conduct questionnaire data collection and focused interviews with patients and daughters
- Edit, code and data enter patient and daughter questionnaires
- Transcribe, code and analysis qualitative focused interviews

Also during Year 3, we have initiated broad dissemination of research findings through conference presentations, invited lectures, and publications. These key research accomplishments are listed below and, copies of relevant materials are appended:

#### ***Conferences and invited lectures:***

(1) A poster entitled “Psychosocial Concerns Experienced by Caregiving Daughters” was presented at the 2002 Era of Hope Department of Defense Breast Cancer Research Program meeting in September in Orlando, Florida. This poster described findings that have emerged from the interviews with caregiving daughters, including their heightened sense of vulnerability and their resultant health-monitoring behaviors. (See Appendix B).

(2) An oral presentation, entitled “Aging Families and Breast Cancer,” was presented at the 130<sup>th</sup> Annual Meeting of the American Public Health Association in November 2002 in Philadelphia, Pennsylvania. The presentation discussed the ways in which women’s perceptions of their own cancer risk can affect the quality of their care provision to an elderly mother. It also examined the impact of the quality of the patient-caregiver relationship on the patient’s psychological functioning. (See Appendix C).



(3) An oral presentation, entitled "Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships", was presented at the 55<sup>th</sup> Annual Scientific Meeting of the Gerontological Society of America in November 2002 in Boston, Massachusetts. The presentation reviewed the challenges of providing informal support and care to an elderly parent and the impact of the breast cancer caregiving experience on the mother-daughter relationship. (See Appendix D).

(4) In December 2002, an hour-long webcast, "Cancer and the Family" addressed the psychosocial issues impacting the family in living with cancer, focusing specifically on the special situation of breast cancer for adult daughters. This online CME-accredited educational webcast training is hosted by Clinical Director's Network, Inc.(CDN) for Community/Migrant Health Center personnel on relevant healthcare issues. This webcast is archived and accessible on the web via CDN's website.

### ***Publications:***

(1) A chapter, "Advances in Cancer Care Impacting Familial Caregiving", Caregiving and Cancer, Ronda Talley, Ruth McCorkle and Walter Baile (Ed.), delineates the psychosocial aspects of recent advances in cancer surveillance, diagnosis and management. Section in chapter on heredity aspects of cancer risk and related caregiving context were directly informed by present investigation (see Appendix E).

(2) As part of a new information resource being developed by the National Cancer Institute, Office of Cancer Survivorship in coordination with the Officer of Education and Special Initiatives for families living with cancer -- Facing Forward series, materials are being prepared that target adult children whose parent has been diagnosed with cancer. These materials, which will be available in 2004, are being informed by the present investigation: "Information needs of adult children of cancer patients: Key themes and strategies". (See Appendix F).

(3) A manuscript, "Psychosocial issues facing adult daughters of breast cancer patients" (working title), will be submitted later this month to *Psycho-oncology*.

### **YEAR THREE: REPORTABLE OUTCOMES**

Year 3 reportable outcomes include the expansion of databases, as more patient-daughter dyads were accrued and interviewed, and dissemination of study findings to date. The salient study findings to date indicate that the cancer diagnosis and their caregiving involvement have broad psychosocial consequences for the adult daughter. Specifically, daughters' narratives illustrate that this experience has impacted their perception of their mother, intensified their bond to their mother, presented challenges in their interactions with their mother, prompted their comprehension of personal cancer risk, confirmed their membership in an undesirable "club", provided a call to action to reduce their personal risk, redefined their personal values, altered

their perceived future, and generated concerns for their children's future. These issues are described in greater detail below and in the appendices:

*Daughters' increased perception of personal cancer risk.* The caregiving daughters report a heightened perception of risk of breast cancer since their mother's diagnosis. More than two-thirds of the daughter's perceive their risk of breast cancer is somewhat or much higher than other women their age. Only 12% of the daughters report that their mother's diagnosis has not affected their perception of their risk of developing breast cancer. Half of the women feel that their risk of developing breast cancer is similar to other women who have a relative with breast cancer, but 30% perceive that their risk is somewhat or much higher. Similarly, most women perceive that their risk is somewhat or much higher than women without a relative with breast cancer. While a family history of cancer is indicative of increased susceptibility to breast cancer, women frequently overestimate their likelihood of developing breast cancer. As one daughter expressed it: "You know, beforehand I felt I had no risk whatsoever. And now, with this, I feel I am much -- I am at a higher risk, given my history." This exaggerated sense of personal vulnerability and strong identification with their mothers has also led some daughters to adopt a more diminished sense of future options and possibilities, i.e., "... it kicked up a lot of fears of being a *daughter*, and that -- okay, I'm next in line."

*Mother's diagnosis was a sentinel event in daughter's life.* A mother's diagnosis can be characterized as a sentinel event, that may prompt daughters to be proactive about monitoring their own health status. Coupled with an increased perception of vulnerability to breast cancer, is an intensification of the mother-daughter bond.

*Challenges of living with breast cancer in the family.* Daughters report experiencing a variety of challenges interacting with their mother following the diagnosis. They explained how their mother's diagnosis altered how they perceived their mothers. One area of concern to daughters is their belief that they need to be a source of support and strength to their mother and they feel a need to refrain from openly sharing with their mother any worries or fears they may have about the illness. Such self-imposed constraints may adversely impact the quality of their interaction and could also increase the stressfulness of their caregiving. Caregiving daughters who are distressed by their mother's illness may also distance themselves from her in an attempt to protect their mother from seeing their distress. The beneficial consequences of social support, particularly the availability of a confidant to whom one can express painful fears and feelings, are well established, however the support daughters provide their mothers may not be without cost to care provider.

*Older patient's caregiving needs.* Advances in treatments are making it possible for many breast cancer patients to receive outpatient care, permitting these women to remain in the community, increasing their potential need for informal caregiving. Extended survival with breast cancer can mean having to cope with the effects of the disease and its treatment over an extended period of time, further increasing the likelihood that illness and treatment-related needs will develop. Given that the absolute number of older women with newly diagnosed breast

cancer continues to rise and the average age at diagnosis is also increasing, the likelihood of comorbidity of other chronic, health-limiting conditions increases as well. It is not surprising then that patients reported receiving illness-related assistance on a variety of activities of daily living (ADLs) and other illness-related tasks. The most frequently reported activities that patients report receiving assistance with are two illness-related activities: "Traveling to medical appointments" and "Obtaining information about breast cancer and its treatment". A substantial portion of the patients also report receiving assistance with a variety of daily living activities. Their caregiving daughters provide a major portion of the assistance that the mothers report receiving.

## CONCLUSIONS

Year 3 field experiences continue to affirm the feasibility of the study procedures (i.e., case identification, sample accrual, and data collection). They also indicate that daughters and mothers are willing to participate in the study and find it meaningful to share their experiences.

The data are informing our understanding of the psychosocial concerns impacting caregiving daughters, following their mothers' diagnosis of breast cancer. Analyses indicate that a rich data set is emerging (see attached presentation and manuscripts in the appendices for more detailed information). These analyses document that cancer is a disease that impacts or affects the family unit, not just the patient. Programs and services need to target the family and support not only the patient but the special needs of family members. While family members may be regarded as part of the care team, they are also affected by the cancer experience. It needs to be more commonly acknowledged/recognized that they hold a dual status.

With the continuing shift of cancer care to community-based care, there is a growing need to understand the costs to the family of the cancer experience. Such information is needed to inform programs that will enable family members, particularly adult daughters, who themselves may be at increased risk for breast cancer, to meet elderly cancer patients' needs for emotional support and practical assistance is paramount. Daughters lacking support themselves may have difficulty dealing with their own exaggerated fears and perceptions of personal cancer risk associated with their mother's disease. This in turn may adversely impact on their relationship with their mothers and impair their ability to provide their mothers with the support and assistance they require. Unsupportive network interchanges can detrimentally impact patients' psychological well-being. It may also impact physical recovery and survival.

**Table 1. Elderly Breast Cancer Patients Contacted Through Year 3 by Eligibility and Participation Status (N=336)**

	<u>%</u>	<u>N</u>	<u>%</u> (Subcategory Distribution)
<b>Eligible Patient-Daughter Dyads:</b>	<b>15</b>	<b>52</b>	
Patient & Daughter agreed	12	41	79
Patient agreed, Daughter refused	3	10	19
Patient agreed, Daughter died prior to accrual	<1	1	2
<b>Ineligible Patient-Daughter Dyads:</b>	<b>34</b>	<b>113</b>	
Patient resides outside of U.S.	<1	1	1
Patient not medically eligible	1	3	3
Patient does not have a daughter	21	71	63
Patient's daughter not a caregiver	11	38	34
<b>Unknown Eligibility:</b>	<b>51</b>	<b>171</b>	
Patient refused contact, returned postcard which indicated "Do Not Contact"	25	83	49
Patient/Daughter refused to complete screener	15	50	29
Unable to contact	10	35	20
Patient died prior to screening	1	3	2

**Table 2. Sociodemographics of Elderly Breast Cancer Patient Sample Through Year 3 (N=41)**

	<u>%</u>	<u>N</u>
<b>Race/Ethnicity</b>		
White, non-Hispanic	71	29
Black, non-Hispanic	5	2
Hispanic	22	9
Other	2	1
<b>Marital Status</b>		
Married	54	22
Widowed	29	12
Divorced	10	4
Separated	7	3
Never Married	--	--
<b>Age</b>		
60-69	61	25
70-79	34	14
80-89	5	2
<b>Extent of Cancer</b>		
Local	68	28
Regional	32	13
<b>Type of Cancer Treatment</b>		
Surgery	37	15
Surgery & Radiation	37	15
Surgery & Chemotherapy	5	2
Surgery, Radiation & Chemotherapy	22	9

## APPENDICES

<u>Appendix</u>	<u>Title</u>
A.	Columbia University Study Protocol IRB Annual Renewal Letters
B.	Poster, Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting
C.	Presentation, American Public Health Association 130 <sup>th</sup> Annual Meeting and Exposition
D.	Presentation, Gerontological Society of America 55 <sup>th</sup> Annual Scientific Meeting
E.	Raveis, V.H. (2003 – In press) “Advances in Cancer Care Impacting Familial Caregiving”, <i>Caregiving and Cancer</i> , Ronda Talley, Ruth McCorkle and Walter Baile (Ed.).
F.	Raveis, V.H. (2004 – in press) “Information needs of adult children of cancer patients: Key themes and strategies”, <i>Facing Forward</i> series, National Cancer Institute Office of Cancer Survivorship in coordination with the Officer of Education and Special Initiatives.

Appendix A:

Columbia University Study Protocol Reapproval Letters



# HERBERT IRVING COMPREHENSIVE CANCER CENTER

Columbia University  
Clinical Protocol Office

March 12, 2003

Victoria Raveis, PhD  
SPH/SMS  
100 Haven Ave, Ste 6A

Re: IRB # 9585, CPMC: Aging families and breast cancer: multigenerational issues

Dear Dr. Raveis:

The above noted protocol was reviewed for annual approval at the March 6, 2003 meeting of the Cancer Center Protocol Review Committee. There were no outstanding issues. Therefore, the study was re-approved for one year.

As you know, the study will still require IRB approval before you can continue to enroll patients or collect data.

Sincerely,

Elizabeth Kaufman, M.P.H.  
Director

EK/ls

CC: IRB  
M. Carrero



COLUMBIA UNIVERSITY  
COLLEGE OF PHYSICIANS & SURGEONS

COLUMBIA PRESBYTERIAN MEDICAL CENTER INSTITUTIONAL REVIEW BOARD  
CPMC IRB

April 1, 2003

Victoria H Raveis, MD  
Department of Public Health  
100 Haven Ave. Ste. 6A Tower #2

**IRB # 9585**

**Title: "AGING FAMILIES AND BREAST CANCER: MULTIGENERATIONAL ISSUES"**

**Expiration Date: March 18, 2004**

Dear Dr. Raveis:

The above-referenced study was reviewed by a convened meeting of the IRB on March 19, 2003.

Upon review, it was determined that additional information was needed to complete the review process. You responded to this request for additional information on March 31, 2003.

Your response was reviewed by:

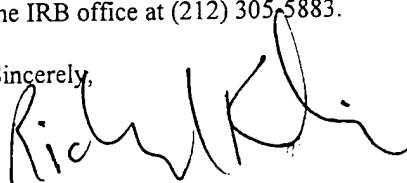
☒ A Board member on March 31, 2003

The following study-related materials were approved:

- ☒ IRB Protocol (undated)
- ☒ Familial Caregiver Consent Form (undated)
- ☒ Spanish Consent Form (undated)
- ☒ Patient Letter (undated)

A request for continuation or completion of the research project is due at least 30 days before this research project's expiration date, unless otherwise requested by the Board. If you have any questions, please call the IRB office at (212) 305-5883.

Sincerely,



Office of the CUHS IRB

IRB/bs

cc: IRB File

enc: Consent Form, Spanish Consent Form, Patient Letter

Appendix B:

Poster, Era of Hope 2002 Department of Defense Breast Cancer  
Research Program Meeting

## PSYCHOSOCIAL CONCERNS EXPERIENCED BY CAREGIVING DAUGHTERS

Victoria H. Raveis, Ph.D.; Tina Sapienza, C.S.W.,  
Monique Carrero, M.A., Sheindy Pretter, Ph.D.

Columbia University, Mailman School of Public Health

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Adult daughters are likely to be a primary source of support and assistance to older women diagnosed with breast cancer, but they have not been a focus of research investigations or supportive services. However, caregiving daughters are likely to be experiencing a high demand for emotional support themselves. The anxiety and concern these women are experiencing over their familial risk status may be compounded by the emotional stress and strain of providing assistance and support to their ill mother, as well as having to deal with the intimate knowledge of their mother's cancer experience afforded by their caregiving experiences. Interviews are being conducted with a sample of 80 older women (aged 60+) receiving treatment for breast cancer and their adult caregiving daughters. As part of the data collection, daughters complete an unstructured open-ended interview. The interviews are audio taped, subsequently transcribed into interview text files and then content analyzed. Data collection is ongoing, but analysis of the interviews conducted to date inform our understanding of the psychosocial concerns impacting the caregiving daughters following their mother's diagnosis of breast cancer. The daughters in the sample talk about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability. This heightened sense of vulnerability is translated for some of these caregiving daughters into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in preventive health behavior. Even those women who previously were aware of the importance of regular check-ups and mammography now see their value brought home. For some women this translates into their being more proactive about their health. This awareness of increased risk is also associated with heightened worry and anxiety and can be expressed in hyper vigilant monitoring. Some caregiving daughters, who have an extensive family history of breast cancer, view their mother's diagnosis as an expected, inevitable event. These daughters often present a stoic attitude about their own risk. The breast cancer diagnosis has also impacted their view of their children's risk and their resultant monitoring behavior.

# Psychosocial Concerns Experienced by Caregiving Daughters

Victoria H. Raveis, Ph.D.

Tina Sapienza, C.S.W.

Monique Carrero, M.A.

Sheindy Pretter, Ph.D.

Annemarie Gregory, B.S.

Poster presented at:

*Era of Hope*

*Department of Defense Breast Cancer Research*

September 25-28, 2002

Orlando, Florida

This study has been funded by a grant from the Department of Defense, Breast Cancer Initiative, *Aging Families and Breast Cancer* [DAMD17-00-1-0215], Principal Investigator: Victoria H. Raveis, Ph.D.

For further information about the study please contact Dr. Raveis at:  
212-304-5563  
email: [vhrl@columbia.edu](mailto:vhrl@columbia.edu)

## **STUDY RATIONALE**

- Adult daughters are likely to be a primary source of support and assistance to older women diagnosed with breast cancer.
- Caregiving daughters are likely to be experiencing a high demand for emotional support themselves.
- The anxiety and concern these women are experiencing over their familial risk status may be compounded by the emotional stress and strain of providing assistance and support to their ill mother, as well as having to deal with the intimate knowledge of their mother's cancer experience afforded by their caregiving experiences.

## **STUDY DESIGN**

- Sample consists of 80 older women (aged 60 and older) receiving treatment for breast cancer at a major urban cancer center and their adult caregiving daughters.
- Patients complete a 40 minute questionnaire, administered over the telephone by a bilingual female research clinician.
- Caregiving daughters participate in a face-to-face research meeting with a bilingual female researcher, completing a 50 minute questionnaire and a 90 minute focused interview.
- Daughter's focused interviews are audio taped, subsequently transcribed into interview text files and then content analyzed.

## SUMMARY

Data collection is ongoing, but analysis of the caregiver daughter interviews conducted to date inform our understanding of the psychosocial concerns impacting the caregiving daughters following their mother's diagnosis of breast cancer:

- The caregiving daughters in the sample talk about their mother being diagnosed with breast cancer as an event that opened their eyes and made them realize their own vulnerability.
- This heightened sense of vulnerability is translated for some of these caregiving daughters into behavioral changes expressed as a resolution to adhere to screening guidelines and engage in preventive health behavior.
- Even those women who previously were aware of the importance of regular check-ups and mammography now see their value brought home.
- For some women this translates into their being more proactive about their health, for others this awareness of increased risk is also associated with heightened worry and anxiety and may be expressed in hypervigilant monitoring.
- For some caregiving daughters, who have an extensive family history of breast cancer, they view their mother's diagnosis as an expected, inevitable event.
- The diagnosis of breast cancer has also impacted how some caregiving daughters' feel about their family's vulnerability to cancer. As with their own sense of heightened vulnerability, these concerns about a daughter's breast cancer risk can also become obsessive thoughts.

## CAREGIVER DAUGHTER SOCIODEMOGRAPHICS (n = 33)

	<u>%</u>
<b>Age:</b>	
< 29	9
30 - 34	27
35 - 39	12
40 - 44	12
45 - 49	27
50 +	12

<b>Race:</b>	
White, Non-Hispanic	73
Black, Non-Hispanic	3
Hispanic	24

<b>Education:</b>	
High School/GED or less	18
Some College	18
College Degree	21
Graduate/Professional Degree	42

<b>Work Status:</b>	
Employed	76

**CAREGIVER DAUGHTER SOCIODEMOGRAPHICS (n = 33)**  
(continued)

	<u>%</u>
<b>Total Number in Household:</b>	
Lives Alone	15
Two	30
Three	15
Four	21
Five or more	18
<b>Marital Status:</b>	
Married	55
Widowed/Divorced/Separated	9
Never Married/Living With Partner	36
<b>Parental Status:</b>	
Is a Parent	53
<b>Number of Children:</b>	
One	12
Two	53
Three	24
Four or more	12



## **DISEASE AND TREATMENT CHARACTERISTICS (n = 33)**

%

### **Extent of Disease:**

<b>Regional/Metastatic</b>	<b>27</b>
<b>Local</b>	<b>73</b>

### **Treatments Received:**

<b>Had Surgery</b>	<b>100</b>
<b>Received Chemotherapy</b>	<b>33</b>
<b>Received Radiation</b>	<b>52</b>

## **DAUGHTERS REPORTED A RANGE OF STRONG EMOTIONAL RESPONSES TO THEIR MOTHER'S DIAGNOSIS**

- Shock, disbelief
- Denial
- Fear, anxiety
- Hopeless
- Panic
- Desperation
- Sadness
- Numb

***Shock, disbelief:***

I was in such a state of shock that you don't -- you freeze, and you don't know what to do.

***Denial:***

At first, I was in, in denial. I just didn't want to -- a lot of things were going through my mind. ...it took me a while for me to really come to terms with reality, that in reality that was cancer.

***Fear, anxiety:***

I got so scared....lots of things go through your head. And they're not the greatest.

***Hopeless:***

All of us, her children and whole family thought that the world had ended because it was a very big thing for us.

***Panic:***

I felt numb at first. Then went crazy.

(Y)ou're panicky; you're splattered -- your head is splattered all over; your thoughts are jumping - -- and you don't *know* what direction to go into, you're just *wild*.

***Desperation:***

I would say just panic, and just -- desperation -- I just started trying to call anybody who I knew who had a wife, a mother, or somebody, to just try to find out as much as I could, to try to help her.

***Sadness:***

I felt very sad at that time. I still do when I talk about that.

***Numb:***

I felt, you know, like I'd been kicked in the stomach. Just the wind knocked out of me.

## **MOTHER'S DIAGNOSIS OF BREAST CANCER WAS A SENTINEL EVENT FOR THE DAUGHTERS**

- Impacting their perception of their mother
- Intensifying their bond to their mother
- Presenting challenges in their interactions with their mother
- Prompting their comprehension of personal cancer risk
- Confirming their membership in an undesirable "club"
- Providing a call to action to reduce their personal risk
- Redefining their personal values
- Altering their future
- Generating concerns for their children's future

### ***Impacting their perception of their mother:***

I felt disoriented. It was the whole mythology of having your parents present and healthy.

For her to get cancer was ...it just didn't make sense in the way I saw my mother. She, she doesn't get sick. . .it just brought home that she's susceptible to -- to disease, and illness.

She is such an independent and strong and capable person, it's been difficult for me to see her in such, what to me looks like a vulnerable position.

It's definitely an emotional -- and a feeling of vulnerability. Once your parents get sick, it changes -- things change. ...Your perception of their immortality -- or mortality. And vulnerability.

### ***Intensifying their bond to their mother:***

I really learned everything about me and my mother. I think I learned what she meant to me more than ever. . . . Because, at that time, I looked at things -- I'd say: What if I have this house? And then I said to myself, So what -- what is it good for? It means nothing. Nothing at all.

It just made me more aware that I need to love every minute I have with her.

### ***Presenting challenges in their interaction with their mother:***

It took me a while for me to really come to terms with reality, that in reality that was cancer. . . . The other problem that I had was, having to *deal* with that struggle, and, at the same time, having to present myself to my mother, as if it -- as if nothing was happening. As if, Oh, well, so what? We deal with it, it happens. Well, I was *burning* inside. I was suffering. But I could never let my mother know that I was worried, because, number one, I *knew* she was worried.

Having to hear what she was going to have to go through . . . it was terrible; I was helpless -- to just have to sit and not be able to do anything, except be there. Which I know is a lot, but it doesn't feel like a whole lot when someone you know is hurting.

I went in to see her after the surgery, and it was just horrible. I just couldn't contain myself. I, I didn't want to stay with her for very long, because I was just so broken up.

### ***Prompting their comprehension of personal cancer risk:***

I think one of the most dominating issues that I had to deal with this time, because of my age, at this point -- I'm older, and what's more of a reality for me is: *This* can happen to me.

You know, beforehand I felt I had no risk whatsoever. And now, with this, I feel I am much -- I am at a higher risk, given my history.

My brothers knew that, for me, it kicked up a lot of fears of being a *daughter*, and that -- okay, I'm next in line...And they *know* that it's a double whammy for me.

This has been an experience that has opened my eyes. It makes you think, "my mother have that illness, I could have it too".

### ***Confirming their membership in an undesirable "club":***

Coming from the family that I came from. . . grandparents who had cancer, et cetera, so I feel like I've always been aware of being vulnerable. . . . my cousins, the daughters of my aunt, who had the breast cancer, said: Oh, well, welcome to the high-risk club -- ha, ha, ha. And I didn't -- it wasn't a club I was very eager to join.

I think I once heard my mother say that she always felt like she was waiting for a train, because of our family history. Like it was a train she was waiting to get on. You know? It was like inevitable. And I guess I feel that way now: "I'm next".

### ***Providing a call to action to reduce their personal risk:***

We sat all together and we decided things that we're going to do . . . things that *we* have to do, as ladies in the house and, you know, in the family, we say: We need to go and have a mammogram for each one of us. You know, try to be more alert.

I think I've -- in general have been a little bit more cautious. I don't want to follow her path in not going to the doctor's -- that I've done -- things I hadn't done recently, like plan to get a physical. Get a mammogram.

### ***Redefining their personal values:***

I noticed that, all of a sudden, my life, and my world -- everything that I planned, in -- nothing meant -- nothing meant anything to me.

Before I used to go out and enjoyed myself a lot. Now when I go out I feel myself preoccupied all the time, worry.

It's like always there, in the back of my mind -- thinking about this illness.

### ***Altering their future:***

What would my life *be* like, knowing that I will have this risk factor, and how would that affect me, and *would* it affect my ability to enjoy my health in my day-to-day life.

Not only I was *afraid* about the anxiety, as much as the prospect of breast cancer -- afraid of what the anxiety would be like of getting a mammogram, or every time, or when there were false positives, or -- you know? Just living your life knowing that there's this thing, and you're at risk for it, and it really could happen.

### ***Generating concerns for their children's future:***

I think about my daughter too. Before this I never thought about it; not my mother, nor my daughter, never.

I am always thinking about my daughter... I always think, "one day she will go to the doctor and find out that she has it too".

Just as I've become more concerned for myself, I've become more concerned for her. ...You know, because -- that's one of the main risk factors is, you know, family history.

## **DAUGHTERS REPORTED A NUMBER OF BEHAVIORAL RESPONSES TO THEIR MOTHER'S DIAGNOSIS**

- Obtain medical assessment of personal risk
- Monitor own health condition
- Obtain mammograms, BSI, pap smear
- Engage in hypervigilance
- Engage in a healthy lifestyle
- Avoid 'risky' medical treatments



### ***Obtain medical assessment of personal risk:***

Since my mother's surgery, I've met with her surgeon and we have spoken about what my options are. And of course the first option, when he was going through what they are was, you know, you can have a prophylactic double mastectomy. And being 33 years old -- ...*That* was not a -- that's not an option that I want to pursue. . . . we just talked about the experimental procedures that they're doing now, the research. He talked a little bit about diet, exercise, self-examination. Having a team. Having a team -- an armed team, so that it does happen to me, we have something early, like we did for my mother.

[The doctor] also suggested that I see a genetics counselor, and speak to her.

### ***Monitor own health condition:***

Now when I go to see the doctor I told him about my mother's cancer. I have a private physician and I always tell him how is everything going with my mother's cancer. He should know.

I will certainly talk to my doctor the next time I see her. And I plan like I did with other areas of my health, to be conscientious about -- about getting regular checkups . . . it's all very new, but I do plan to get more information.

I need to go and see that doctor more often. I don't do that. I take care of everybody, but I -- most of the time neglect myself.

### ***Obtain mammograms, BSI, pap smear:***

I feel like sort of this urgent need that I need to start mammograms and start a baseline and keep an eye on it.

I *never* did self-examinations. And I -- not quite once a month, but I've actually started to do them, which is great and -- I want to go get a mammogram

I do my mammograph, and Pap Smear, my things. I try to check myself on time because you don't know. I try to have my exams according to what they say because I might not have it, but my mother already has it. . . it doesn't hurt to get checked.

### ***Engage in hypervigilance:***

Now any pain that I have I run to the doctor. The other day it happened and I went to my private doctor. . . I just had the mammography done a couple of weeks before that. It is really frightened. ...[A]ny little pain make me think about it. Before, I never thought about it.

### ***Engage in a healthy lifestyle:***

I have become a little bit more concerned about what I eat, and exercising.

Maybe I'll start eating a little healthier, and -- but I think I lead a very, I would say "healthy" life. I'm not a person who do outrageous thing -- drink or smoke, or any of those things.

Now I know that I need to be more careful. I have to, you know, be more alert about things because...especially with what I eat and my nutrition which is very important.

Well, I do exercise on a daily basis. .. I try to watch what I eat.

### ***Avoid 'risky' medical treatments***

The first thing my husband said to me, when my mother's slides came back positive, was that, you know: Forget about ever going on hormone therapy, ever taking estrogen. I'm just telling you right now. I don't care how many hot flashes you get or how cranky you get, or whatever, just forget it. *Not* for you.

Appendix C:

Presentation, American Public Health Association 130<sup>th</sup> Annual  
Meeting and Exposition



## Aging families and breast cancer

Victoria H. Raveis, PhD, Joseph L. Mailman School of Public Health, Columbia University, Center for Psychosocial Study of Health and Illness, 100 Haven Avenue, Suite 6A, New York, NY 10032

Limited attention has been given to cancer in the aged, especially among various minority populations. Hispanic elderly primarily rely on family for care in times of illness and female relatives are likely to be the primary source of support and assistance. However, first degree relatives of breast cancer patients are at increased risk for breast cancer themselves. This heightened sense of risk has been associated with increased anxiety levels. A substantial proportion of women at-risk for familial breast cancer hold exaggerated perceptions of their risk and for some the perceived threat is associated with a paralyzing sense of cancer-related worry that severely impacts their ability to function on a daily basis. The anxiety and concern these women may experience may be exacerbated by the strain of providing assistance to their ill mother. Those who are extremely distressed and worried may be incapable of providing the assistance and emotional support their ill parent requires. At-risk women's level of psychosocial adjustment to their familial risk status may also have an adverse effect on their interpersonal relationship with the mother, contributing to unmet patient needs and conflicted support. Such occurrences can impede a cancer patient's recovery. This presentation will discuss how women's perception of their cancer risk effects the quality of their careprovision to their elderly mother. It will also examine the impact of the quality of the patient-caregiver relationship on the older patient's psychological functioning. The data is drawn from interviews conducted with a sample patient-caregiving daughter dyads (n=40).

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**Abstract ID#:** 47997

**Password:** 791906

**Program Selection:** Gerontological Health

**Topic Selection:** Formal and Informal Caregiving

**Keywords:** Breast Cancer, Aging

**Learning Objectives:** Attendees will: 1) Understand the impact of breast cancer on the aging family 2) Appreciate the psychosocial stresses of informal caregiving 3) Appreciate the the impact of perceived risk of cancer on the quality of the patient-caregiver relationship

**Submitter Email:** vhr1@columbia.edu

**Target Audiences:** Counselors and social workers working with other cancer patients and their families  
Oncologists treating older patients  
Pastoral care workers working with older families  
Genetics counselors

**Presentation Format:** NoPreference



MAILMAN SCHOOL  
OF PUBLIC HEALTH  
Columbia University

## Aging Families and Breast Cancer

Victoria H. Raveis, Ph.D., Monique Carrero, M.S.,  
Tina Sapienza, C.S.W., Sheindy Pretter, Ph.D.

This study has been funded by grants from the Department of Defense, Breast Cancer Initiative and the  
New York State Breast Cancer Research and Education Fund NYS DOH C017945

### Study Rationale

- Adult daughters are likely to be a primary source of support and assistance to older women diagnosed with breast cancer.
- Caregiving daughters are likely to be experiencing a high demand for emotional support themselves.
- The anxiety and concern these women are experiencing over their familial risk status may be compounded by the emotional stress and strain of providing assistance and support to their ill mother, as well as having to deal with the intimate knowledge of their mother's cancer experience afforded by their caregiving experiences.

## Study Design

- Sample consists of older women (aged 50 and older) receiving treatment for breast cancer at a major urban cancer center and their adult caregiving daughters.
- Patients complete a 40 minute questionnaire, administered over the telephone by a bilingual female research clinician.
- Caregiving daughters participate in a face-to-face research meeting with a bilingual female researcher, completing a 50 minute questionnaire and a 90 minute focused interview.
- Daughter's focused interviews are audio taped, subsequently transcribed into interview text files and then content analyzed.

## Patient Disease and Treatment Characteristics

	<u>%</u>
Extent of Disease:	
Regional/Metastatic	26
Local	74
Treatments Received:	
Had Surgery	100
Received Chemotherapy	31
Received Radiation	51

### Activity Domains – Patients Receiving Illness-Related Assistance

<u>Most Frequently Reported Activities</u>	<u>%</u>
Traveling to medical appointments	89
Obtaining info about breast cancer & treatment	86
Heavy housekeeping	66
Grocery shopping	60
Light housekeeping	57
Cooking/Meal preparation	49
Shopping for clothes & household items	49
Home healthcare tasks	43

### Activity Domains – Caregiving Daughters Providing Assistance to Patient

<u>Most Frequently Reported Activities</u>	<u>%</u>
Traveling to medical appointments	83
Obtaining info about breast cancer & treatment	80
Grocery shopping	49
Light housekeeping	43
Shopping for clothes & household items	37
Heavy housekeeping	34
Cooking/Meal preparation	32
Filling out insurance forms	31

## Caregiving Daughters' Perceived Risk of Breast Cancer

In your opinion, compared to other women your age, what are your chances of getting breast cancer?

<i>Somewhat lower</i>	12%
<i>The same</i>	18
<i>Somewhat higher</i>	53
<i>Much higher</i>	18

How has your relative's diagnosis of breast cancer affected your perception of your own chances of developing breast cancer?

<i>Had no effect on me</i>	15%
<i>Somewhat more at risk</i>	53
<i>A lot more at risk</i>	32

## Caregiving Daughters' Perceived Risk of Breast Cancer

What are your chances of developing breast cancer...

Compared to other women with a relative with breast cancer?

<i>Much lower</i>	03%
<i>Somewhat lower</i>	18
<i>The same</i>	50
<i>Somewhat higher</i>	21
<i>Much higher</i>	09

Compared to other women without a relative with breast cancer?

<i>Much lower</i>	03%
<i>Somewhat lower</i>	06
<i>The same</i>	15
<i>Somewhat higher</i>	50
<i>Much higher</i>	27



## **Cancer Diagnosis Prompts Comprehension of Personal Cancer Risk**

"You know, beforehand I felt I had no risk whatsoever. And now, with this, I feel I am much -- I am at a higher risk, given my history."

"For me, it kicked up a lot of fears of being a *daughter*, and that -- okay, I'm next in line."

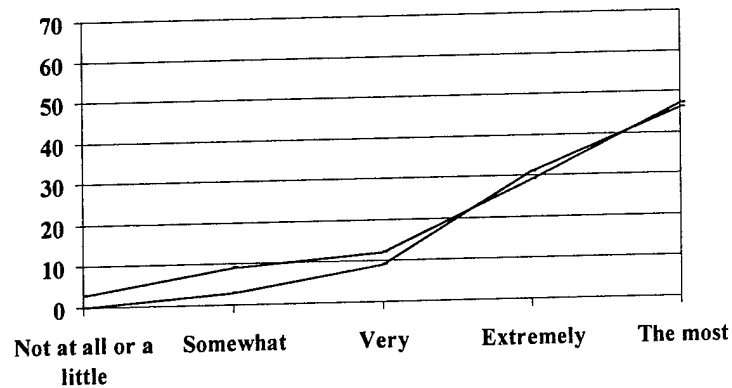
"This has been an experience that has opened my eyes. It makes you think, "my mother have that illness, I could have it too"."

## **Cancer Diagnosis Intensifies Bond to Their Mother**

"I think I learned what she meant to me more than ever. . . . Because, at that time, I looked at things -- I'd say: What if I have this house? And then I said to myself, So what -- what is it good for? It means nothing. Nothing at all."

"It just made me more aware that I need to love every minute I have with her."

### How close is your relationship with your relative?

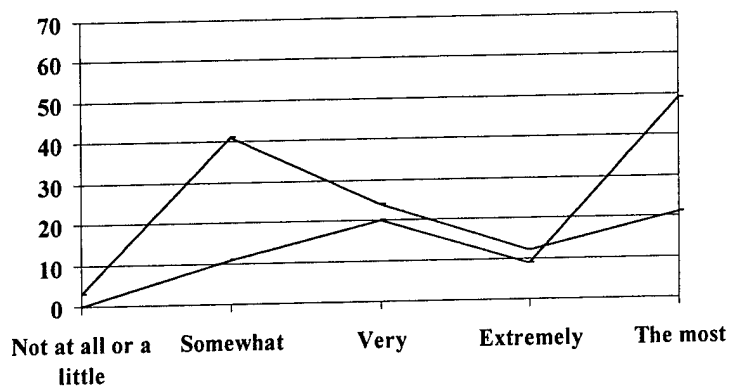


### Cancer Diagnosis Presents Challenges Interacting with Their Mother

"It took me a while for me to really come to terms with reality, that in reality that was cancer. . . and, at the same time, having to present myself to my mother, as if it -- as if nothing was happening. As if, Oh, well, so what? We deal with it, it happens. Well, I was *burning* inside. I was suffering. But I could never let my mother know that I was worried, because, number one, I *knew* she was worried."

"I went in to see her after the surgery, and it was just horrible. I just couldn't contain myself. I, I didn't want to stay with her for very long, because I was just so broken up."

### How much do you tell your relative everything?



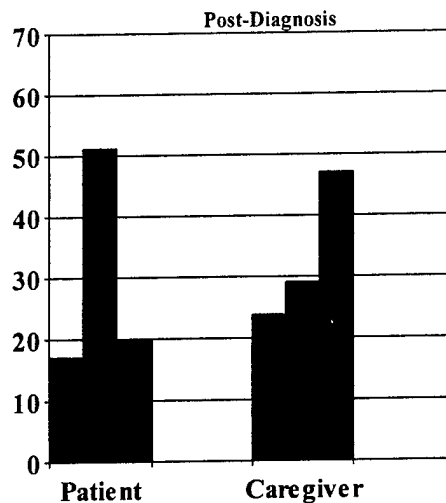
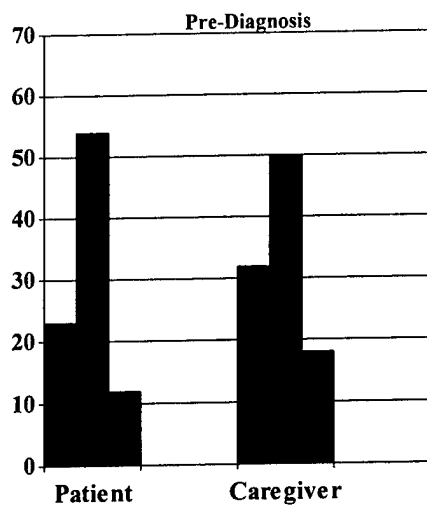
### Cancer Diagnosis Impacts Perception of Their Mother

"For her to get cancer was ...it just didn't make sense in the way I saw my mother. She, she doesn't get sick. . .it just brought home that she's susceptible to -- to disease, and illness."

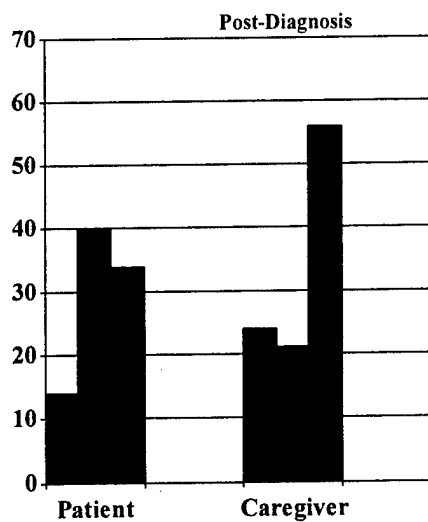
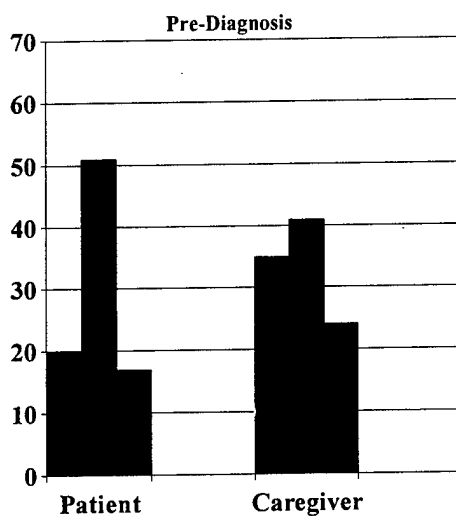
"She is such an independent and strong and capable person, it's been difficult for me to see her in such, what to me looks like a vulnerable position."

"Once your parents get sick, it changes -- things change. ...Your perception of their immortality -- or mortality. And vulnerability."

### Who tends to be the boss in the relationship?



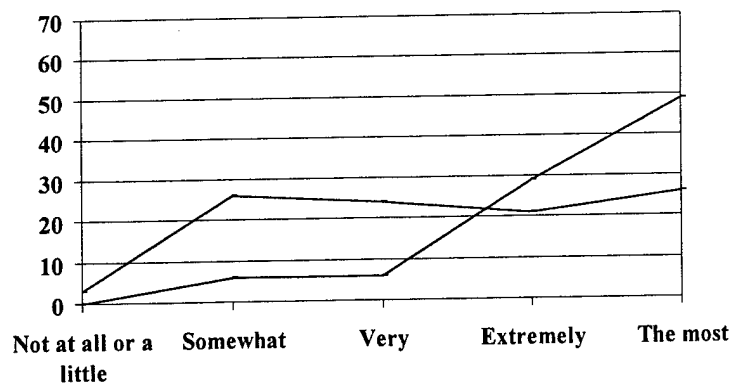
### Who tells the other person what to do more often?



## **Cancer Diagnosis Alters Interactions with Their Daughter**

"....My daughter was so supportive and extremely compassionate. It finally occurred to me one day to question how she was coping with all of this. She was pregnant during my diagnosis and had trouble during pregnancy.....I decided I could not keep getting upset and sharing all of my feelings with her."

### **How satisfied are you with your relationship with your relative?**



Appendix D:

Presentation, Gerontological Society of America 55<sup>th</sup> Annual  
Scientific Meeting

## “Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships”

Victoria H. Raveis, Ph.D.; Sheindy Pretter, Ph.D.; Tina Sapienza, C.S.W.; Monique Carrero, M.A.; and Annemarie Gregory, B.S.

Adult daughters are a primary source of support and assistance to older women diagnosed with breast cancer. However, daughters experience a high demand for emotional support themselves. The anxiety and concern they experience over their familial risk status is compounded by the emotional stress of providing assistance and support to their ill mother and their need to deal with the intimate knowledge of their mother's cancer experience. Interviews with 80 older breast cancer patients and their care giving daughters inform our understanding of the psychosocial concerns and relationship changes (e.g. becoming closer to the ill parent) associated with an aging parent's breast cancer diagnosis. Not only was the diagnosis an event that made daughters realize their own vulnerability but this heightened sense of risk translated into risk management behavioral changes. For some this knowledge impacted their view of their children's vulnerability and highlighted a need for multigenerational health promotion activities.

Learning Objectives: (1) Understand the psychosocial impact of breast cancer on the aging family; (2) Comprehend the impact of perceived risk on the quality of family relationships and careprovision

To be presented at The Gerontological Society of America's 55<sup>th</sup> Annual Scientific Meeting, Boston, Mass., November 24, 2002

### Caregiver Daughter Sociodemographics (Cont.)

	%
<b>Education:</b>	
High School/GED or less	18
Some College	18
College Degree	24
Graduate/Professional Degree	41
<b>Work Status:</b>	
Employed	74
<b>Marital Status:</b>	
Married	59
Widowed/Divorced/Separated	9
Never Married/Living With Partner	32

### Caregiver Daughter Sociodemographics (Cont.)

	%
<b>Parental Status:</b>	
Is a Parent	56
<b>Number of Children:</b>	
One	16
Two	47
Three	26
Four or more	11
<b>Total Number in Household:</b>	
Lives Alone	15
Two	29
Three	15
Four	21
Five or More	21





# **Familial Breast Cancer Risk and the Aging Family: Challenges and Changes in Relationships**

Victoria H. Raveis, Ph.D., Sheindy Pretter, Ph.D.;  
Tina Sapienza, C.S.W.; Monique Carrero, M.S.;  
and Annemarie Gregory, B.S.

This study has been funded by grants from the Department of Defense, Breast Cancer Initiative and the  
New York State Breast Cancer Research and Education Fund NYS DOH C017945

## **Caregiver Daughter Sociodemographics**

	%
<b>Age:</b>	
<29	9
30-34	27
35-39	12
40-44	12
45-49	27
50 +	12
<b>Race:</b>	
White, Non-Hispanic	77
Black, Non-Hispanic	3
Hispanic	21

## **Factors Impacting Informal Caregiving in Cancer**

- With increased survival, due to earlier detection and more aggressive treatment, patients and families may be dealing with illness or treatment-related needs over an extended period of time.
- Diagnostic cancer testing and treatments previously performed on an inpatient basis are being increasingly administered in outpatient settings and in the home.
- Increased age at diagnosis increases the likelihood of patients having co-morbid health conditions, increasing their home care needs.

## **Cancer and Older Adults**

- Cancer is a major cause of morbidity and mortality in older Americans, with its incidence increasing dramatically.
- Cancer is now more aggressively screened for, detected earlier, and more aggressively treated in older adults.
- Advances in cancer detection and treatment are increasing older cancer patients' survival.
- Not only is the absolute number of older adults with newly diagnosed cancer continuing to rise, but the average age at diagnosis is increasing as well.

## Daughters Reported a Range of Emotional Responses to Diagnosis

- ***Shock, disbelief***

"I was in such a state of shock that you don't -- you freeze, and you don't know what to do."

- ***Denial***

"At first, I was in, in denial. I just didn't want to -- a lot of things were going through my mind. ...it took me a while for me to really come to terms with reality, that in reality that was cancer."

## Daughters Reported a Range of Emotional Responses to Diagnosis

- ***Panic***

"I felt numb at first. Then went crazy."

"(Y)ou're panicky; you're splattered -- your head is splattered all over; your thoughts are jumping --- and you don't *know* what direction to go into, you're just *wild*."

- ***Desperation***

"I would say just panic, and just -- desperation -- I just started trying to call anybody who I knew who had a wife, a mother, or somebody, to just try to find out as much as I could, to try to help her."

## **Daughters Reported a Range of Emotional Responses to Diagnosis**

- ***Fear, anxiety***

"I got so scared....lots of things go through your head. And they're not the greatest."

- ***Feeling without hope***

"All of us, her children and whole family thought that the world had ended because it was a very big thing for us."

## **Daughters Reported a Range of Emotional Responses to Diagnosis**

- ***Sadness***

"I felt very sad at that time. I still do when I talk about that."

- ***Numb***

"I felt, you know, like I'd been kicked in the stomach. Just the wind knocked out of me."

## **Mother's Diagnosis Redefined Daughter's Personal Values**

"I noticed that, all of a sudden, my life, and my world -- everything that I planned, in -- nothing meant -- nothing meant anything to me."

"Before, I used to go out and enjoyed myself a lot. Now when I go out I feel myself preoccupied all the time, worry."

"It's like always there, in the back of my mind -- thinking about this illness."

## **Mother's Diagnosis Provided Daughters a Call to Action to Reduce Risk**

"I think I've -- in general have been a little bit more cautious. I don't want to follow her path in not going to the doctor's -- that I've done -- things I hadn't done recently, like plan to get a physical. Get a mammogram."

"We sat all together and we decided things that we're going to do . . . things that we have to do, as ladies in the house and, you know, in the family, we say: We need to go and have a mammogram for each one of us. You know, try to be more alert."

## **Cancer Diagnosis Altered Daughter's Perceived Future**

"What would my life *be* like, knowing that I will have this risk factor, and how would that affect me, and *would* it affect my ability to enjoy my health in my day-to-day life."

"Not only I was *afraid* about the anxiety, as much as the prospect of breast cancer -- afraid of what the anxiety would be like of getting a mammogram, or every time, or when there were false positives, or -- you know? Just living your life knowing that there's this thing, and you're at risk for it, and it really could happen."

## **Cancer Diagnosis Alters Generated Concerns for Future of Daughter's Children**

"I think about my daughter too. Before this I never thought about it; not my mother, nor my daughter, never."

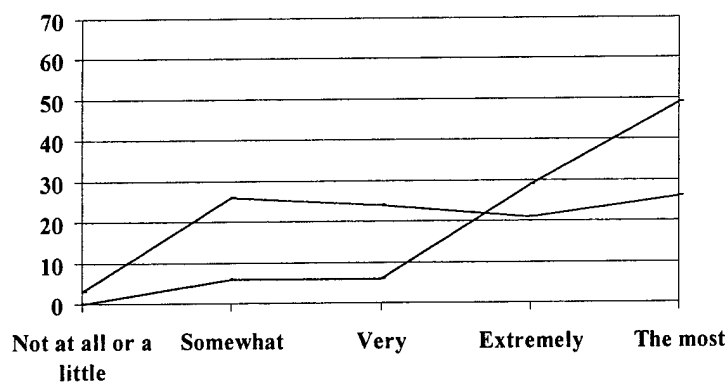
"I am always thinking about my daughter... I always think, 'one day she will go to the doctor and find out that she has it too'."

"Just as I've become more concerned for myself, I've become more concerned for her. ...You know, because -- that's one of the main risk factors is, you know, family history."

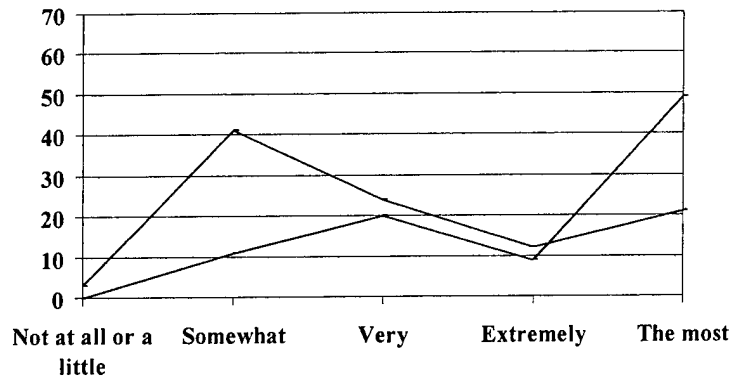
## **Mother's Diagnosis of Breast Cancer Was a Sentinel Event For Daughters**

- Impacting their perception of their mother
- Intensifying their bond to their mother
- Presenting challenges in their interactions with their mother
- Prompting their comprehension of personal cancer risk
- Providing a call to action to reduce their personal risk
- Redefining their personal values
- Altering their perceived future
- Generating concerns for their children's future

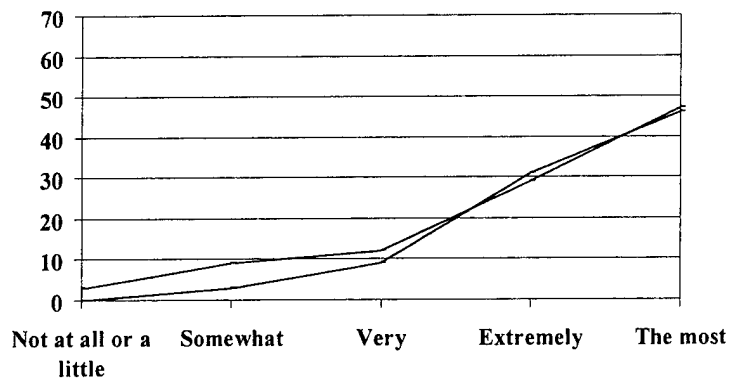
## **How satisfied are you with your relationship with your relative?**



### How much do you tell your relative everything?



### How close is your relationship with your relative?





Appendix E:

Raveis, V.H. (2003 – In press) “Advances in Cancer Care Impacting Familial Caregiving”, *Caregiving and Cancer*, Ronda Talley, Ruth McCorkle and Walter Baile (Ed.).

**"Advances in Cancer Care Impacting Familial Caregiving"**

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## Introduction

Recent developments in detecting, diagnosing and treating cancer have contributed to reduced disease progression and increased survival. The current 62% 5-year relative survival rate for cancers diagnosed between 1992-1998 represents a statistically significant increase from the 52% 5-year survival rate for cancers diagnosed between 1983-1985 [ACS, 2003]. Advances made in the management and treatment of the disease have also slowed disease progression, reduced the severity and frequency of treatment side-effects and increased the number of patients who remain in the community while their illness is managed on an outpatient basis. Such developments have affected both the magnitude and quality of survival following a cancer diagnosis.

As in other illness situations requiring informal support and assistance, the family is integral to the care and support provided to persons receiving treatment for cancer. Informal caregiving to cancer patients can encompass emotional support, financial aid and the provision of services ranging from instrumental aid and assistance with personal care, to health care tasks and mediation with formal care providers [Raveis, et al., 1998]. Cancer treatments create multiple demands for caregivers as they assist patients in dealing with the physical and psychological consequences of surgery, chemotherapy and radiation, in addition to disease-related needs.

In understanding how developments in the treatment and management of cancer have impacted informal caregiving, it is important to keep in mind that cancer is not a single disease; it is a collection of different types, all characterized by uncontrolled growth and spread of abnormal cells. Not all advances in the treatment and management of one type of cancer are applicable to other types of cancers. The symptoms, treatment, illness course, life expectancy, and prognosis

can vary with the type of cancer and its site (i.e., body location). Thus, caregiving needs will differ and families will not necessarily be dealing with the same set of treatment- or illness-related demands and stressors. However, within this cancer-specific variability, all families face a shared set of challenges imposed by the illness. These challenges include coping with uncertainty, dealing with the losses engendered by the illness and care provision.

This chapter will focus on a number of important ways that advances in understanding cancer and developments in its treatment and management have re-defined families' cancer-related challenges. *An understanding of how these developments impact informal caregiving touches upon areas that are the subject of other chapters in this volume. This chapter will review some of these areas as they relate to current cancer treatment and management practices.*

### **Treatment and Management Advances Expand Family's Caregiving Role**

Several trends in health care have coalesced to expand the scope and duration of the family's involvement in the care of cancer patients throughout the disease course. The national trend toward "dehospitalization" of medical care encompasses cancer therapy as well as advances in treatment that make it possible for many cancer patients, even seriously-ill individuals, to remain in the community while receiving care. Diagnostic testing and treatments previously performed on an inpatient basis are increasingly administered in outpatient settings and in the home. For example, improved methods of medical management have increased patients' tolerance of highly cytotoxic chemotherapeutic agents, making these treatments possible on an outpatient basis. Use of infusion pumps and vascular access devices have made it feasible for patients to be maintained in the home while receiving chemotherapy [Crawley, 1990]. Complex chemotherapeutic routines and radiation treatments previously

requiring an inpatient stay are routinely delivered in outpatient clinics and physicians' offices [Mor, Allen, Siegel and Houts, 1992]. Radiation implants concentrate timed delivery of radiation over a sustained interval, permitting patients to remain at home and reducing the need for multiple clinic visits. While these changes are generally welcome, they place added duties on the family, broadening the scope of their caregiving tasks. The family has now become directly involved in both rehabilitative care and delivery of active treatment, a not inconsequential expansion to their set of care responsibilities.

The initial diagnosis period is a time of intense stress and crisis for cancer patients and their families, characterized by a series of unrelenting demands and intense activity. During this period, families are confronted with numerous difficult decisions that may necessitate the mastery of new information to make an informed choice. Embedded within this decision process is the challenge of coming to terms with the uncertainty as to whether a specific choice will achieve the desired outcome. As a consequence of recent efforts to broaden dissemination about cancer care options and enable wider access to them, families' responsibilities in this area have intensified. For example, greater access to information about cancer treatment and clinical trials enables family members to weigh the merits of additional treatment options that may not be routinely offered. This necessitates searching out available information, evaluating its merits, advising on treatment decision-making, and perhaps seeking out appropriate health care providers and intervening on behalf of the patient to ensure access to care. This represents an expansion of the health care advocacy tasks that families' assume and can require skills and/or resources (e.g. time, access to information sources) that may not be readily available. In some instances a family's well-intended efforts may inappropriately raise expectations for treatment

options that are not suitable for the patient's condition and this can add to the stresses the family is experiencing.

In recent years, improvements in diagnostic methodologies have contributed to cancers being diagnosed at an earlier stage. This improvement in cancer detection facilitates initiating treatment at a more optimal point in the disease course, when there is a greater likelihood of a cure or effecting a long-term survival. Advances in tools and approaches for managing and treating cancer have also contributed to reduced mortality and increased survival for all cancers [NCI, 2001]. Consequently, the chronic phase or adaptation phase of the disease course, i.e., the period of survival that follows the initial medical intervention, has lengthened for an increasing number of cancer patients and their families. As the initial crisis of the cancer diagnosis and the upheaval surrounding the beginning of treatment begins to abate, a major challenge families face is living with the uncertainty of the disease course. Generally, the efficacy of cancer treatment cannot be fully assessed until a time interval has passed. This period of watchful waiting can be an increasingly stressful experience for patients and family members. Even during a period of remission, hope of a "cure" is tempered by the threat of recurrence.

During this chronic phase of the illness course, the patient may experience not only the symptoms of the disease itself, but also the sequelae of the treatment received. Disease progression and intensified treatment may make a patient more and more debilitated. The major caregiving tasks during this phase are meeting the illness and treatment-related needs of the patients. Even if the prognosis for long-term survival is good, family members may need to come to terms with disease or treatment-related changes from the patient's pre-illness functioning and need to adjust to losses imposed by the illness, including changes in roles and lifestyles. The

shock and disbelief that family members experience during the initial diagnosis period may block out consideration of the consequences of living with cancer.

Extending survival does not necessarily mean that the person is ultimately restored to a pre-illness level of functioning. From a care perspective, improvements in cancer survival may mean that more families are involved in a lengthier period of care provision, attending to disease and treatment-related care needs and facing the financial, insurance and employment concerns associated with survivorship. It is also important to note that even with advances in cancer treatment, most cancer therapies are not without some adverse health effect. With longer cancer survival periods, more families will need to deal with the emergence of long-term treatment-related consequences that may develop over time and necessitate further care provision. For example, as a consequence of the successes in recent decades in the treatment of childhood cancers, there is a growing body of adult cancer survivors who are now facing a set of new health problems, including the development of new cancers related to the cancer therapies they received during childhood [NCI, 2003]. In these instances the total cancer-related caregiver burden may span decades and can encompass different caregiving cohorts (i.e., parental caregivers during childhood and spousal or adult child caregivers in adulthood).

### **Treatment and Management Advances Add to Uncertainty of Cancer Survivorship**

Medical and technological advances in cancer care have made it possible to extend life and delay death for a growing number of patients. Although these issues have always been present in cancer care, treatment decisions are now more complex. There exists the potential for some cancer treatment options to extend life at an undesirable cost to the patient and family in

terms of medical, physical, psychological and/or social impacts. Families are now faced with needing to consider the risks and benefits of specific therapies (e.g., minimally-invasive surgery, prophylactic therapy, etc.) in conjunction with quality-of-life considerations (e.g., the choice of potentially toxic, time-intensive interventions that might prolong life versus less aggressive measures that would improve short-term quality of life but not extend it).

Understanding the family impact of advances in the clinical management of cancer entails the need to also consider the patient's quality of life. For example, prostate cancer is a very slow growing type of cancer. Patients may live for years with the cancer and die from other causes before it progresses to a more advanced stage. When deciding about what treatment option should be followed, consideration needs to be given to treatment-related side effects that can profoundly impact upon patients' quality of life. Even when a treatment may not entail any physical side-effects, the emotional distress associated with a treatment choice can still adversely impact patients' and families' psychological well-being. In instances where the prostate cancer is being managed with watchful waiting, patients and families can experience emotional distress associated with knowing that cancer is present and that no clinical efforts are being made to slow down its growth process [Freeman, 1993].

As advances in the care and management of cancer continue to occur, the current opportunities and future promises of new therapies can contribute to the uncertainties patients and families confront. Patients and families not only need to live with the uncertainty over the efficacy of treatment received, but they may also wonder about the correctness of their treatment choice. When the treatment option has undesirable side-effects or patients have not benefitted



from the treatment, families may experience regret, and/or guilt over a perceived poor treatment choice or missed opportunities for an alternative treatment approach. Families' decisions on further cancer therapy may be further influenced by an expectation, heightened by current treatment advances, of beneficial therapies forthcoming in the future. This may compel families to expend efforts to extend survival at all costs for a possible future cure.

### **Advances in Understanding Cancer Have Re-defined Who Is a Patient**

Recent advances in understanding cancer and improvements in the screening and diagnosis of cancer are making it possible to detect an increasing number of pre-cancerous conditions and identify, for a growing number of cancers, persons with an inherited susceptibility. As public awareness of an hereditary component to some types of cancer has grown, investigations have documented increased fear of cancer and a heightened perception of cancer risk among persons whose relatives have had cancer [Kelly, 1983; Wellisch et al., 1991; 1992]. Genetic testing can identify individuals with genes associated with certain cancers, such as breast, ovarian and pancreatic cancer, who are then advised to undergo special surveillance for developing this disease [NCI, 2003]. As testing becomes more widely available, for a wider variety of cancers, increasing numbers of relatives of cancer patients may be motivated to undergo genetic testing to assess their own risk following their relative's cancer diagnosis. These developments have broadened the criteria for who and when someone is a patient.

As a consequence, a growing group of individuals are faced with living with the uncertainty of when or if they may develop cancer. This has important implications for families'

caregiving responsibilities, for while this advance facilitates surveillance and can contribute to cancer survivorship, it also creates additional caregiving responsibilities. At risk individuals are in need of ongoing emotional support, informational guidance interpreting the treatment and monitoring options, and advocacy in negotiating the health care system throughout the surveillance period. Caregiver support and assistance may be required following each diagnostic procedure. And while for some cancers, the treatment option may be "watchful waiting", for other cancers, the options may include prophylactic treatment. For example, for some women at elevated risk for breast cancer the recommended prophylactic treatment may be use of tamoxifen, which is associated with increased health risk. For other women with specific mutations to the BRCA1 and BRCA2 genes current research evidence suggests their cancer risk can be reduced by prophylactic oophorectomy (removal of the ovaries) once their child-bearing is complete [NCI, 2003].

The caregiving needs may become more complex when at-risk family members are caring for a relative with cancer. The family caregivers are likely to be experiencing a high demand for emotional support themselves. The anxiety and concern they experience over their familial risk status may be compounded by the distress and strain experienced providing assistance and support to their ill family member. Several studies have indicated that daughters whose mothers have had breast cancer develop exaggerated concerns that they will also develop breast cancer (or a strong belief in biological determinism) [Kelly, 1983; Wellisch et al., 1991, 1992] as well as daughters' anxiety-laden identification with their mother's health [Hyland et al., 1984]. Such fears may adversely affect the quality of their relationship with their mother -- promoting conflicted or strained interactions [King et al., 1993; Collins, 1996]

-- impeding their ability to provide emotional support and practical assistance to their mothers, and increasing the stressfulness of their caregiving experience. Buckley [1977] reported that in their interactions with their post-adolescent daughters, mothers with advanced breast cancer perceived their daughters as emotionally distant and aversive to discussing the cancer.

### **Caregiving and the Treatment of Cancer in the Elderly**

Life expectancy has increased dramatically in recent decades due in part to improved nutrition, better access to health care and medical advances that permit individuals to survive potentially fatal acute health events. The last quarter of the twentieth century has seen a doubling in the size of the elderly population. Cancer is a major cause of morbidity and mortality in older adults, its incidence increasing dramatically with age [Edwards et al, 2002]. Persons aged 50-64 have cancer rates seven- to sixteen-times higher than younger adults, with rates for persons aged 65-74 two- to three-times higher [Edwards et al., 2002]. As the population ages, the number of older adults with newly diagnosed cancer will continue to rise, as will the average age at diagnosis. As a consequence, the burden of cancer, already high in older adults, will continue to grow. It is anticipated, based on cancer incidence rates and U.S. Census Department population projections, that the number of cancer patients 65 and older will double in the next thirty years. Perhaps even more significantly from a caregiving perspective, the number of cancer patients aged 85 and older is expected to increase fourfold between 2000 and 2050 [Edwards, 2002].

Cancer is now more frequently screened for, detected earlier, and aggressively treated in older adults, as reflected in National Institute of Health's policy shift regarding the former

exclusion of the elderly from most clinical trials . Given these developments, the number of elderly persons living with cancer is substantial. About 60% of cancer survivors are 65 or older, with 32% of the survivors 75 and older [Edwards, 2002]. The current average age of cancer survivors is 68 for men and 64 for women [NCI, 2002a].

Age-related physical infirmities may complicate cancer care. Cancer management approaches that work well in younger adults may not readily apply to older adults. Elderly patients may be on other medications that can interact with their cancer therapy [Edwards, 2002]. The physiological changes in organ function associated with aging place the older cancer patient at increased risk for treatment-related toxicities [Lichtman and Villani, 2000] and co-morbid conditions can increase the risk of adverse treatment-related side-effects [Balducci and Yates, 2000].

The recent trends in health care delivery (i.e., the shift from inpatient to outpatient care, shortened in-patient stays ), have specific implications for the care of older adults. Age adds a layer of complexity to cancer caregiving not present in other cancer care situations. The elderly are likely to have more extensive, complex and long-term caregiving needs. As a consequence of the physiological changes associated with aging (e.g., decreased stamina, physical strength, frequent comorbidity, and heightened disability), older cancer patients may require a longer period of rehabilitation from treatment, experience more severe or longer-lasting side-effects, and have difficulty negotiating the health care system and advocating for the best care.

In addition, given that the number and severity of chronic health conditions increases with age, the cancer diagnosis may not initiate the family's caregiving role, but rather expand upon or add to an already existing set of care responsibilities. With older adults, co-morbid

conditions are common and families may have already been providing care to their elderly relative for other health conditions when the cancer was diagnosed.

### **Progress in Cancer Care Reduce Caregiving Burden**

As developments in the care and treatment of cancer have re-shaped the caregiving situation, some of the burdens that families have experienced in the past have been reduced or eliminated. The National Cancer Institute's (NCI) efforts in the 1980's initiated the dissemination of technological developments in cancer treatment and control from major cancer centers to the broader medical community. The Community Clinical Oncology Program (CCOP) is an example of one organizational mechanism, established by NCI, to facilitate technology transfer to community oncology programs and permit advances in cancer care to be available in community settings [Kaluzny et al., 1989]. Such efforts also expanded to access to NCI clinical trials.

These changes have made it more feasible for patients and their families to participate in clinical trials and to obtain the benefits of current developments in cancer care within the setting of their local community. Previously, clinical trial participation or access to specialized and/or state-of-the-art cancer therapies have generally only been available in major clinical and research cancer centers. Families could undergo considerable financial expense and incur time and social costs taking up temporary residence near the treatment center or traveling back and forth to the center for what would typically be a lengthy cancer treatment period.

A number of biomedical advances have changed cancer care and reduced the burden of cancer on the family. Technological advances in cancer imaging and molecular sensing have

enabled earlier, more accurate cancer diagnoses, make it possible to treat cancer at a less advanced state, individualize therapies and use fewer invasive interventions [NCI, 2003]. These developments translate into reduced caregiver burden.

Improvements in the precision of cancer screening tools have made it possible to detect cancer at an earlier, more curable stage, reducing the scope and duration of familial caregiving. An additional advantage to increased precision is that it more accurately detects persons with cancer. This advance reduces the number of persons who unnecessarily undergo further diagnostic procedures because the screening test is too inclusive. For example, current screening for prostate cancer is a blood test that measures the level of prostate-specific antigen (PSA). PSA levels can be elevated even in the absence of cancer and a biopsy is needed to determine whether cancer is present. Protein profiling is an emerging technology that shows promise of more accurately classifying men with prostate cancer at a very early stage with fewer false positives and unnecessary biopsies [NCI, 2003]. Providing greater precision at the screening level reduces caregiver burden. Apart from the financial costs associated with additional diagnostic tests, there is the emotional distress and anxiety experienced over a possible cancer diagnosis, and there can be recovery-related caregiving needs associated with invasive diagnostic procedures.

Refinements in imaging technology over the last few decades have provided much clearer and more detailed images of organs and tissues. These developments have broadened the range of medical options for diagnosis, management and treatment of cancer, translating into reductions in caregiver tasks. For example, advancements in computed tomography (CT) and ultrasound have made possible the insertion of long, thin needles deep within the body to biopsy organs, reducing the need for more invasive surgical diagnostic procedures. Minimally-invasive

diagnostic and surgical procedures reduce inpatient stays and permit many procedures to be performed on an outpatient basis and in physicians' offices. These procedures reduce the length of the recovery period, minimizes scarring and permanent surgical changes.

Progress in understanding the disease process has also informed the adoption of less mutilating surgical procedures that have been found to provide similar success in cancer survival. Less radical surgical approaches, such as lumpectomy, not only diminish the risk of postoperative complications such as bleeding and infection, but also cut down on the formation of scars, decrease the rehabilitation period, and reduce permanent side-effects. These procedural changes have alleviated some of the burdens associated with receiving medical treatment and translate into reduced caregiving needs as the period of recovery and degree of treatment-related side-effects are minimized.

Advances have been made in reducing the adverse effects of cancer treatments. Greater precision in the delivery of radiation treatments have minimized side-effects (e.g., skin irritation, nausea, diarrhea, hair loss, loss of energy), reducing the amount of normal tissue receiving the radiation. Radioactive implants concentrate delivery of radiation to a small area over a sustained period, limiting the affected area and reducing the need for office visits for receipt of treatment. Chemotherapy regimes are now less cytotoxic making it possible for many patients to receive most of their treatment on an outpatient basis and reducing treatment-related side-effects emerging from damage to normal tissues. Infusion pumps permit timed delivery of chemotherapy over days/weeks reducing need for multiple clinic visits. Other advances in medication delivery options (e.g., patches) further simplify medication adherence. Substantial progress has also been made in comfort care addressing treatment or disease-related side-effects, further reducing the

distress and concern experienced by family members.

Biological therapies, a more recent addition to the standard cancer treatments of surgery, chemotherapy and radiation, use the body's immune system to fight cancer and reduce or repair treatment-related side-effects. Most cancer therapies inadvertently damage or destroy normal cells as well as cancer cells resulting in temporary (e.g., baldness) or permanent (e.g., sterility) treatment-related side-effects. In some instances, aspects of cancer therapy may be life-threatening such as in the destruction of patient's immune system prior to bone-marrow transplantation. This class of "smart" drugs selectively targets the cancer cells, leaving normal cells alone, reducing treatment-related side-effects and limiting the scope and duration of patient's caregiving needs.

Emerging technological advances in biotherapy are also informing the development of immunotoxins and vaccines that utilize the immune system to attack existing cancer cells. Although the number of these drugs approved for cancer therapy are limited, a substantial number are under development. They hold a promise to significantly reduce cancer burden. Gleevec, recently approved for the treatment of chronic myeloid leukemia and gastrointestinal stomal tumor, is an example of this new class of drug therapy. Gleevec works by blocking the rapid growth of white blood cells. Its side effects have been found to be less severe than traditional therapies and it has been shown to have a beneficial impact on patients when other treatments have failed.

### **Caregiver Education and Training Needs**

There is a lack of clinical consensus regarding the best treatment options for the optimal



management of cancer. Also lacking is an understanding of the quality of life impact of efficacious cancer treatments. While efforts are being made to move toward a consolidation or synthesis of best approaches, families are faced with having to obtain and evaluate evidence and information that they require to make an informed choice. Specialized knowledge is necessary to fully understand treatment options. In making decisions about treatment options families may be faced with needing to select an option that could close off the possibility of future alternative treatments. For example, prior therapies can exclude patients from enrollment in a specific clinical trial. As discussed earlier, families continually face uncertainty in dealing with cancer, and information may help inform the best possible choice. The stage of the lifespan when the individual is diagnosed with cancer adds an additional layer of complexity to the cancer treatment decisions. For example, weighing the benefits of current therapies while needing to evaluate the possibility of future lost options may be particularly problematic when children are diagnosed with cancer and the potential for current decisions may have a long-term impact on their future health and care options.

Cancer caregivers often need to become mediators and advocates within the medical system, seeking information to assure the best choice of treatment options and advocate for needed social services. Such mediation efforts and information-seeking are typically performed by adult children for elderly parents. These activities may be very time-consuming and stressful and are likely to increase as options for management and treatment of cancer care broaden. Specialized care or access to the latest developments in treatment are likely to be very fragmented and may involve family members in considerable advocacy and coordination efforts. For example, the costs of care in clinical trials are not routinely covered by all insurance carriers.

The decision to participate in a clinical trial may need to be weighed against the economic burden participation in a trial could entail. Understanding what is involved in these treatment alternatives and what rights and options may be available to the family is not an area about which families may be adequately informed.

The Internet is an expanding resource for cancer information and education. Web technology has the advantage of being able to provide access to up-to-date advances and current treatment options, and expert information. NCI's Office of Cancer Communication has made efforts to increase access to and use of cancer information through enhanced NCI databases and user-friendly web sites that provide information not only about cancer treatments but also clinical trials. It is also can facilitate access to an extensive referral system and help caregivers identify websites for specialized care.

It is important to bear in mind, though, that the full range of educational and informational resources may not be readily available to all families impacted by cancer. Low literacy, low income and non-English speaking populations are underserved by technological advances in information dissemination such as the Internet.

Advances in the management and delivery of cancer treatments not only permit the portability of the treatment delivery (i.e., out of the hospital or clinic and into the home), but also require the caregiver to be involved in the delivery of technical or complex care routines that previously could only have been provided on an intensive care unit. The shift to home-based care means that families are involved in a broad range of specialized care routines, such as overseeing the delivery of complex drug regimes, being responsible for monitoring drug responses, adjusting dosages and maintaining the drug delivery system. These are tasks for which families may not

have received prior preparation or training and initially are ill-equipped to perform. This has important implications not only regarding the families' financial, emotional and social resources, but also in terms of the stresses they experience providing ongoing care. Medical equipment or in-home devices requiring maintenance by family may raise concerns and fear over potential mishandling and adverse consequences to the patient's well-being.

In a study of familial caregivers to advanced cancer patients, over two-thirds of the familial caregivers reported having to learn the skills that would enable them to manage the patient's activities of daily living (i.e., assist with the patient's ambulation, handle bowel and bladder disturbances, manage the patient's pain, nutritional needs and dietary requirements) and general comfort [Grobe et al., 1981]. Family caregivers would benefit from systematic efforts to provide education and training in basic nursing and home medical care techniques, symptom interpretation, managing treatment and illness-related side-effects, as well as training in operating and maintaining in the home specialized equipment or devices.

Caregiver instructional materials are limited, especially culturally appropriate or low literacy materials or those that address treatment technology that caregivers may be required to use and maintain. Training programs for family caregivers tend to be sparse and localized, usually institutionally-based. Demonstration programs which may provide specialized or targeted training and support are time-limited. There are a number of local, regional and national resources that families can assess to obtain additional information and support. For example, Cancer Care, Inc. is national organization that provides supportive services for cancer patients and their families. These services include educational programs, printed materials, telephone, Internet contact, counseling and information and referrals provided in-person (through area

offices).

### **National Policy Recognizing Family Caregiver Situation**

Family members are increasingly being relied upon as the major source of support and assistance to persons with cancer. Given recent advances in the care and management of cancer, the scope and duration of family caregiving is expanding. Family caregivers are often challenged in balancing this care with their other responsibilities as a spouse, parent and worker. As part of a growing recognition on a national level that the complex challenges families face in their caregiving may impair their ability to provide adequate care or maintain care over a lengthy time interval, a number of legislative developments were enacted to facilitate families' managing these diverse demands, such as the Older Americans Act, which includes the National Family Caregivers Support Program. The program is designed to provide families with respite care, training, information and referral sources. The Family and Medical Leave Act facilitates employees to take a leave from work to care for family members. The National Coalition for Cancer Survivorship report, "Imperatives for Quality Cancer Care", states that the patient and family should be seen as a unit of care and notes the necessity of addressing the impact and consequences of cancer care on family caregivers [Clark et al., 1996]. Policy statements issued by the National Cancer Institute define cancer survivors as anyone touched by cancer and note the need to focus attention on understanding the needs of families of cancer patients and develop interventions based on these needs [NCI, 1999; 2004].

### **Future Advances in Cancer Care: Implications for Caregiver Policy, Practice, Research, Education and Training**

**Policy.** Efforts to expand on respite care, tax relief, employee caregiver assistance programs, and insurance coverage for experimental procedures (including clinical trials and complementary or alternative medicine, comfort care), illness-related "out-of-pocket" expenses -- could reduce some of the caregiving burdens experienced by families. More than three decades ago, the National Cancer Act of 1971 set in motion a comprehensive national plan to reduce cancer-related morbidity and mortality. Through the years this act has been re-authorized and updated to reflect emerging developments and priorities in cancer care and research. Activities set in motion by this act have contributed to the current developments in the care and management of cancer and have indirectly influenced the current caregiving challenges facing families today.

In 2002, the "National Cancer Act of 2002" was proposed in the U.S. Senate [Dunn, 2002]. Although legislative progress on this bill is still ongoing, it contains a number of provisions that directly relate to developments in the care and management of cancer that if enacted, would directly impact upon the familial caregiving situation. The bill proposes financial incentives to pharmaceutical firms to encourage development of drugs that would target narrow genetic or cellular mutations. This could produce more effective treatments for specific cancers, increase survivorship and reduce treatment-related side-effects. The legislation is also proposing that routine medical costs associated with participating in clinical trials would be covered by all insurers (private, Medicaid and Medicare). This provision would reduce the financial burden that some families face when patients participate in a clinical trial and could reduce a barrier to clinical trial participation. The bill also contains a provision to authorize a new education and training program overseen by the Health Resources and Services Administration (HRSA). This

program would bolster the cancer care workforce to enhance the provision of cancer care in under-served communities and to encourage the recruitment of health care professionals to specialties with anticipated shortages. The challenges that families face in reaching treatment decisions, coordinating care and navigating the health care system may be mitigated somewhat with the provision to authorize insurance coverage for a physician who would coordinate and provide overall management of a patient's cancer care.

**Practice.** The movement to extend advances in cancer management and care to all populations affected by cancer acknowledges the unequal burden of cancer borne by minority populations [Institute of Medicine, 2001]. For these efforts to be successful, cultural sensitivity needs to be incorporated into the care delivery system. Various racial and ethnic groups hold differing expectations than their health care providers as to the exchange of information and the treatment decision-making process. These patterns may impact patients' and families' understanding of the implications of different treatment decisions, the way that their decisions are made, and the choices that are selected.

Financial costs of cancer are likely to continue to be a burden to patients and their families and may require families to face some difficult treatment choices. Cancer-related care costs are expected to increase as new, more advanced and technological complex therapies become routinely available [NCI, 2001]. Economic costs of current cancer care can be considerable and advances in cancer treatment may pose additional economic barriers to continued care. For example, currently oral medicines that are commonly used to treat breast and prostate cancer are not covered by Medicare [NCI, 2001]. Patients may need to take some of the newly-developed cancer drugs, such as Gleevec, a recently developed "smart" cancer drugs, to

control their leukemia or gastrointestinal tumor growth, for the rest of their lives. Gleevec is an oral medication with a high monthly cost. Continued use of this medication could impose a financial burden on families over time and limit the families who could afford to provide this life-sustaining care.

**Clinical Research.** A number of the currently ongoing areas of clinical investigation have the potential to reduce the burden of cancer caregiving in the future. Developments in pharmacology show future promise for effective drug therapies that can be initiated in persons with conditions that are a precursor to cancer. For example, in preliminary studies with the drug celecoxib, the drug was effective in reducing the number of colon polyps in patients with a pre-cancerous condition, familial adenomatous polyposis (FAP) [NCI, 2002]. Clinical trials are evaluating its efficacy with related conditions. Success in reducing the incidence of cancer readily translates into a reduced need for care provision. Work is also progressing on the development of a variety of cancer prevention vaccines that utilize an individual's immune system to evoke an immune response that targets cancer-causing agents. One such agent in which early clinical vaccine trials are being conducted is the sexually-transmitted human papillomavirus (HPV) which has been linked to cervical cancer [NCI, 2002]. With an arsenal of effective cancer vaccines, a family's future caregiving responsibility could focus on pro-active tasks, such as ensuring participation in cancer screening.

There also is continuing effort to further reduce the adverse consequences of current treatment approaches. Studies are continuing on a "mini-transplant" option for bone marrow transplantation. This experimental procedure takes advantage of the immune properties of the donor stem cells to kill the cancer cells while tolerating the patient's normal cells. A key benefit

of this approach is that patients receive a much lower dose of radiation, sufficient to suppress the patient's immune system, but not high enough to destroy the patient's bone marrow. Most patients who received a mini-transplant were able to leave the hospital the same day as the procedure, unlike conventional bone marrow transplants in which patients are hospitalized in intensive care for two to three months [NCI, 2002]. Should this procedure be shown to be effective in phase III clinical trials, it could expand the option of bone marrow therapy to patients who are too infirm or debilitated to undergo conventional bone marrow procedures. The caregiving burden associated with bone marrow transplants would also be substantially reduced as the mini-transplant approach reduces the length and intensity of the recovery period.

**Psychosocial Research.** Even with advances in cancer treatments, most therapies produce some measure of adversity. NCI acknowledges the need to devote additional research effort on expanding the scientific knowledge base on cancer survivorship, to understand the adverse late effects of current and new cancer treatments, specifically with regard to the health status and quality of life of patients in their post-treatment years [NCI, 2003]. There is also a need to conduct in-depth cross-sectional investigations and longitudinal studies on psychosocial and practical "costs" of cancer treatment to the family caring unit. Little is known about "quality of life versus extended survival" from a family's perspective; the caregiving challenges facing the families of long-term survivors and families' psychosocial concerns living with a genetic risk factor for cancer risk.

Cultural norms and religious traditions may also impact upon preferences for life-extending care. For example, Blackall et al. [1999] documented that although Korean American



elders do not want to be maintained on life support, they believe that it is their children's duty to insist that they be kept alive as long as possible, a philosophy shared by Chinese and Asian Pacific families [Yeo, 1995]. Similarly, a religious view held among many African Americans regards pain and suffering as something to be endured as part of a spiritual commitment [Crawley et al., 2000]. Steinhäuser and colleagues [2001] documented that African American and other non-white ethnic groups were significantly more likely than whites to agree with the importance of using all available treatments, no matter what the chance of recovery. Garrett et al. [1993] reported that elderly (65+) community-dwelling blacks were more likely than whites to feel that "how long" they lived was more important than "how well" they lived (25% vs. 6%).

**Education and Training Needed.** An effective familial caregiver can bolster patients' well-being, alleviating demands on the health care system. However, the viability of the informal care system is dependent upon families' skills and abilities. Deficiencies in their performance can seriously impact on both the patient and family member's well-being, threatening the quality of care and sufficiency of care on a long-term basis. Instructional programs and materials for diverse caregiving groups need to be accessible throughout the disease course and updated to reflect technological developments

## **Conclusions**

In understanding the current and future impact of advances in cancer care on the familial caregiver, it is important to bear in mind that the family has a dual status, both as a provider of support and assistance to the patient, i.e., member of the care team, and at the same time as a person impacted by the cancer experience and in need of support and assistance. As advances in

cancer care continue to transform cancer into a chronic disease, more individuals will be living with and affected by the cancer experience. Clinical care to cancer patients needs to incorporate the needs and resources available to the family care unit.

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## Appendix F:

Raveis, V.H. (2004 – in press) “Information needs of adult children of cancer patients: Key themes and strategies”, *Facing Forward* series, National Cancer Institute Office of Cancer Survivorship in coordination with the Officer of Education and Special Initiatives.

“Information needs of adult children of cancer patients: Key themes and strategies”

*Facing Forward* series

National Cancer Institute Office of Cancer Survivorship  
in coordination with the Officer of Education and Special Initiatives

Victoria H. Raveis

(2004 – expected publication)



## **A. Cancer in the family precipitates comprehension of personal risk**

**Behavioral response.** With growing public awareness of a hereditary component to some types of cancer, those who perceive themselves at risk may seek to reduce their cancer risk by incorporating lifestyle changes and/or by monitoring their health status. For adult children, their parent's cancer experience may also have created a call to action, i.e., behavior that is designed to reduce their risk or promote early detection.

*Mary's mother was diagnosed with an advanced stage of breast cancer. Her mother had noticed a lump on her breast but delayed seeing a doctor because she hoped that it would go away. Her mother's experience has made Mary aware of the importance of having routine medical exams and undergoing breast cancer screening. Mary says that she does not want to follow her mother's behavior. She realizes that it has been awhile since she has had a routine physical and intends to schedule one soon. She is also planning on having a mammogram.*

**Emotional response.** When someone in the family has cancer, this experience may increase other family members' cancer fears and heighten their perception of cancer risk. This event can also contribute to family members expressing a sense of inevitability and loss of control over their future. For adult children, a sense of personal vulnerability and identification with their parents' illness condition may lead them to adopt a more diminished sense of future options and possibilities and prompt a perception of "being next in line."

*Carmen explained that before her mother's breast cancer, she felt no risk whatsoever. But now, she feels differently. She recalls that her grandmother had died from breast cancer and now her mother has developed it. As Carmen explains, her mother's illness has created a lot of fears that she, as the daughter, is next. It has also made Carmen afraid that she may have passed this risk on to her infant daughter, Julia. She worries that one day Julia may also develop breast cancer.*

### **Strategies:**

- Seek an informed medical opinion regarding personal risk to establish surveillance and monitor activities that are age- and risk-appropriate
- Obtain information available from NCI or other health care organizations about recommended lifestyle changes to promote healthy living and reduce cancer risk (e.g., diet and nutritional practices, exercise regimes)
- Find out what community support resources (counseling, informational, educational) are available for persons at risk
- Speak to a therapist or counselor
- Join a support group for persons at risk

## **B. Cancer experience impacts parent-child relationship**

**Necessitates role reversal.** Cancer and its treatments can create a broad range of care needs. The role reversal inherent in adult children providing care and assistance to an aging parent may elicit a variety of responses. Parents' responses to their loss of independence and dependence on others for help can be reflected in a range of emotional responses – moodiness, depression, anger or withdrawal. This can lead to strains in their relationships with family members and leave adult children feeling hurt and frustrated in their attempts to help. The role reversal that occurs during the illness experience may be difficult to reverse once initiated. During the survivorship period, although caregiving needs may diminish, the ill parent may receive more assistance than is required and experience this family support as over-control. Adult children may have to work towards finding a balance between providing their ill parents with the support and care they require and allowing them autonomy and independence.

*An elderly widow, Irene lived by herself. Following cancer surgery, her daughter moved in with her for a couple of weeks to help out. Irene and her daughter seemed to fight all the time. Irene had always prided herself on being independent and self-sufficient. She hated that she needed help and disliked having her daughter tell her what to do. Her daughter was upset that her mother appeared to resent her efforts to help. It appeared that Irene and her daughter argued about everything – when Irene needed to rest, what foods she should eat, how the daughter should do the household chores. As soon as Irene was well enough to live on her own, her daughter went back to her own apartment. Prior to Irene's surgery, Irene and her daughter had a good relationship; now, though, it is strained. Her daughter is hurt that Irene did not appreciate her efforts more. Even now that Irene is fully recovered, they seem to argue a lot.*

**Alteration in communication and interaction.** The cancer experience can also impact a family's pattern of communication and interaction. It is not uncommon for family members to be protective of an ill relative by withholding information from them that they fear may be upsetting. Adult children may feel that they need to be a source of support and strength to their ill parent and refrain from openly sharing with their parent any worries or fears they may have about the illness. Such self-imposed constraints can alter patterns of communication with the ill parent, limiting the range of topics that are discussed and hindering an open sharing of information and concerns. This can contribute to strained interactions and adversely impact the quality of adult children's relationship with their parents.

*Although his mother had finished her treatment a few months ago, John finds that every time he talks to her she turns the conversation back to her illness. He doesn't think that it is good for her to keep going over and over all the details of her surgery and how sick the chemotherapy had made her feel. This was a very distressing period for the whole family and John is puzzled why his mother keeps dwelling on these events. He used to enjoy speaking with his mother and now he finds himself making excuses to cut their conversations short.*

**Alters adult children's perception of their parent.** When a parent is diagnosed with a life threatening illness, adult children may be faced with viewing their parents from a different perspective. The illness experience may force adult children to consider their parent's mortality and vulnerability.

*When Bill's father was diagnosed with cancer and underwent treatment, Bill was shaken. He had always seen his father as invincible and strong. For Bill, his father was someone who did not get sick, so the cancer diagnosis was a shock. He still recalls how upsetting it was to see how weakened and dependent his father was after cancer surgery. Bill is struggling to come to terms with the realization that his father is susceptible to disease and illness.*

**Strategies:**

- Find out what community support resources (counseling, informational, educational) are available for families
- Speak to a therapist or counselor, share concerns with a spiritual advisor
- Join a support group

**C. Cancer in older adults**

**Treatment and recovery is more complicated in older adults.** Although cancer is now more frequently screened for, detected earlier, and aggressively treated in older adults, age-related physical infirmities complicate cancer care. Cancer management approaches that work well in younger adults may not readily apply to older adults. Elderly patients may be on other medications that can interact with their cancer therapy. The same physiological processes that slow down the progression of cancer in older adults may also impede the recovery process. Families may not fully comprehend that the completion of active treatment does not necessarily end the illness event, especially for older patients. Recovery from cancer and its treatment can be a lengthy process for older adults and there may even be occasional setbacks. Rehabilitation may be more difficult or complicated and restoration to pre-illness functioning may not be possible to achieve.

*Julie's mother needed to undergo cancer surgery and a regime of chemotherapy. It has now been six months since the surgery and three months since her mother's last chemotherapy treatment, but whenever Julie visits, she finds that her mother is still tired and lacking in energy. Her mother has also lost interest in her favorite past-time, gardening, and is still not eating well. Julie had thought that once her mother's treatment was over things would go back to normal. Julie is worried that her mother may never fully recover and concerned about how exhausted and weak the cancer and its treatment have left her mother. Julie had a friend who had breast cancer and recalls how quickly her friend seemed to recover once her treatment was completed. It seemed that it was only a few weeks after her friend's surgery before she was back at work full-time and*

*dining out with friends. Julie doesn't know what she can do about her mother.*

**Co-morbidity increases the complexity of the care situation.** Age adds a layer of complexity to cancer caregiving not present in other cancer care situations. The number and severity of chronic health conditions increase with age. The cancer diagnosis may not initiate a family's caregiving role, but rather expand upon or add to an already existing set of care responsibilities. With older adults, co-morbid conditions are common and adult children may have already been providing care to their elderly parent for a different health problem or condition when the cancer was diagnosed. Co-morbid conditions can increase the risk of adverse treatment-related side-effects. Adult children may be unable to fully relinquish the caregiving role once treatment ends because the cancer experience may have precipitated other health problems.

*Marsha and her father were always close. Two years ago, after he developed a heart condition, he moved into Marsha's home. Although his illness restricted his activities somewhat, he enjoyed being able to spend more time with his grandchildren. But since his cancer he's distanced himself. He's depressed and doesn't let anyone in. Marsha has found the last month the most difficult. Even his grandchildren can't distract him. Not only is his behavior upsetting to her, but she is finding it very hard to explain to her children why their grandpa isn't enjoying spending time with them anymore. They think that they have done something to upset him.*

**Strategies:**

- Accompany your parent on his/her next medical appointment, communicate your concerns about your parent's functioning and recovery to the health care team
- Work with the health care team to establish realistic long-term goals for your parent, identify interim goals to mark progress
- Access community support resources, including aging-specific resources that may help in your parent's recovery or rehabilitation or improve quality of life

**D. Impact of care provision on the family**

**Multiple roles.** Adult daughters are likely to be at that stage in the life cycle where they are experiencing multiple role demands, due to marital obligations, child-rearing responsibilities and work requirements. As a consequence, they are often challenged in balancing their care provision with these other responsibilities. This can adversely impair their ability to provide adequate care or maintain care over a lengthy time interval. Adult children may experience feeling over-burdened or sandwiched between their other responsibilities in their daily lives. With families of their own, they may find that their involvement in their parent's care has adversely impacted their own family life, as they have had to reduce the time they spend with other family members, such as their spouse or children. Adult children who are married or have children themselves may find that their spouse or children are resentful of the time they spend

with the ill parent. They may also experience feeling guilty about not being able to devote as much time as they previously have done to their spouse and children because of their current caregiving involvement.

*Josie had just gone back to work after her second child when her mother was diagnosed with cancer. She and her husband could not afford for her to take another leave from work so they worked out a schedule so that a neighbor watched the children whenever Josie's husband wasn't home to take care of the children. Josie was able to spend this time helping her father take care of her mother. It has been really hard for Josie, because while she feels good that she is able to be there for her parents, she regrets that she is spending so little time at home with her young children and her husband. Although her mother has finished her treatment, it has left her functionally impaired and she will continue to need daily assistance.*

**Long-distance caregiving.** Education, employment and marriage have contributed to families being geographically disperse. When a serious illness such as cancer occurs, it may not be feasible for adult children in distant locales to provide any long-term, hands-on care. In such instances, adult children may engage in long-distance caregiving and the daily care responsibilities may fall to nearby relatives.

*Mary lives across the country from her parents. When her dad was diagnosed with cancer, she tried to help as much as possible, but it has been difficult long-distance. A young mother of three, she has only been able to make two brief visits to her parents since her dad's diagnosis. Although unable to be there as much as she wanted to be, Mary tried to help as much as possible. She searched the Internet for all the latest information about her dad's cancer and spoke with her health care specialists so that she was able to assure her parents that her dad was getting the best possible care. Since her parents were retired, Mary and her husband also helped out financially. Mary called her parents frequently throughout her father's treatment and recovery period. These calls helped her feel closer to her parents and what they were going through and her parents seemed to appreciate her efforts. However, her sister June, is upset with her. June helped her mother take care of her father and resents that Mary only made two brief visits and did not stay long enough to help out.*

**Strategies:**

- Set reasonable limits on what you can do, don't set standards that are impossible to achieve
- Identify resources in your parent's community that can assist with care provision or respite care
- Schedule visits so that it will provide respite for other family members engaged in daily care
- A number of legislative developments have been enacted to facilitate families'

managing their diverse demands, such as the Older Americans Act, which includes the National Family Caregivers Support Program. The program is designed to provide families with respite care, training, information and referral sources. Another legislative development is the Family and Medical Leave Act. This act facilitates taking a leave from work to care for family members.